DECONSTRUCTING WOMEN AND ENSURING LIFE:
Trajectories in facing breast cancer in Brazil and in Germany

Inaugural Dissertation

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I dedicate this work to all my beloved ones who have struggled against cancer — sometimes winning the battle, and other times persisting until the end.

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I am grateful for the gift of life, and for the choices that I have so far been able to make in order to get here! I have a special warmth for my origins, and my great-great-grandparents and great-grandparents, who moved to Brazil from the European continent at the start of the 1900s. These relatives chose an adventure to the new world, to work in farming or in the emerging industries, and here met Native Brazilians and the newly freed African slaves. From this intermingling of peoples, my grandparents' and parents' generations emerged, followed by my own and my daughter's generations. I am happy and privileged to spring from this union between races, and a love that surpasses, eternally and respectfully, coming together with the art of human coexistence. Along the way, our family changed their forms of social insertion, and some went from factory laborers to intellectuals and self-employed professionals. However, we have remained united in cherishing dignity and the different parts that each of us play, ensuring human existence on this planet. To my dear ones, my greatest gratitude — especially for the values cultivated within our families.

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“(...)

Maria, Maria
Is the sound, is the color, is the sweat
Is the higher and slower dosage
Of people who laugh things off
When they are supposed to be crying
And end up not living, simply enduring

But you must be strong
You must persist
You must be determined, always
Those who wear the marks on their bodies
Maria, Maria
Mix pain and joy

But you must be smart
You must have grace
You must always dream
Those who wear the marks on their skin
Have the strange habit
Of believing in life

(…)”

(Fernando Brant & Milton Nascimento)

RESUMO

A pesquisa é um estudo qualitativo, do qual participaram 15 mulheres brasileiras (entre 35 e 65 anos) e 12 mulheres alemãs (entre 50 e 81 anos), todas passando pelos tratamentos do câncer de mama; cujo diagnóstico tivera sido obtido dentre 6 e 24 meses, na ocasião em que uma entrevista única foi feita com cada uma delas. A questão central da pesquisa foi: Quais são os principais desafios encontrados pelas mulheres brasileiras e pelas alemãs mediante a descoberta e os tratamentos do câncer de mama? Os objetivos foram fazer comparações internas dentre os dois públicos pesquisados, e depois comparações externas, envolvendo as experiências das mulheres de ambos os países, com o adoecimento. Os resultados encontrados no estudo, que adotou a Teoria Fundamentada nos Dados como ferramenta teórico-metodológica, discorreram sobre as diferenças para obtenção do diagnóstico – que no Brasil foi majoritariamente buscado a partir do momento no qual as mulheres fizeram o autoexame das mamas, e identificaram por si mesmas alguma alteração; e na Alemanha, quando elas atenderam à carta convite, do Seguro de Saúde, para fazerem a mamografia de rastreamento. A revelação da doença também foi investigada, e os estigmas do câncer de mama se revelaram maiores para as alemãs do que para as brasileiras adoecidas. Outro fator de destaque foram as diferenças dentre os tratamentos prescritos, sendo que no Brasil todas as mulheres passaram pelas quimioterapias, e somente duas delas receberam as radioterapias. Já na Alemanha, todas as mulheres passaram pelas radioterapias, e somente um terço das entrevistadas receberam as prescrições médicas para as quimioterapias. Além disso, diferentes posicionamentos – no que se refere às identidades, conforme o interacionismo simbólico, e em consonância com a Psicologia Social – , foram encontrados no estudo, e são discutidos no trabalho, que foi divido em três partes. Por fim, considera-se que alguns posicionamentos das mulheres de ambos os países, trouxeram para elas ganhos, e certa diminuição do sofrimento; quando elas conseguiram uma transcendência do próprio self, autoaceitação, e uma assimilação que transpôs o eu, para além da identificação com à doença. Entretanto, outros posicionamentos trouxeram prejuízos, e aderência ao sofrimento - especialmente quando o self não se adequou à nova realidade das perdas físicas e/ou psicológicas.

Palavras-chave: Câncer de Mama. Teoria Fundamentada nos Dados. Experiências. Identidade. Psicologia Social.

ABSTRACT

This research is a qualitative study, in which 15 Brazilian women (between 35 and 65 years of age) participated, as well as 12 German women (between 50 and 81 years), all of whom were undergoing breast cancer treatment; the diagnosis of which had been obtained between 6 and 24 months prior to the occasion when a single interview was carried out with each one. The central question of this research was: What are the main challenges met by the Brazilian and German women when facing the discovery and treatment of breast cancer? The goals were to carry out internal comparisons regarding illness among the women from each country, and later external comparisons, involving the experiences of the women in both countries. The results found in the study, which adopted Grounded Theory as a theoretical-methodological tool, discuss the differences in obtaining diagnoses — which in Brazil were, for the most part, sought after the women carried out self-examinations of the breasts, identifying alterations themselves; and in Germany, after answering the Health Insurance invitation letter for a screening mammogram. The moment of sharing news of the disease was also investigated, with the sick German women exhibiting more stigma regarding breast cancer than the Brazilian women. Another key factor was the difference between prescribed treatments, as in Brazil all the women went through chemotherapy, with only two receiving radiotherapy. In Germany, on the other hand, all the women went through radiotherapy, with only a third of interviewees receiving a medical referral for chemotherapy. Additionally, different positioning was found in the study in terms of identity, according to symbolic interactionism, and relating to Social Psychology; these are discussed in the work, which is divided into three parts. Finally, it is considered that certain positionings of the women in both countries brought them gains, and diminished suffering up to a point; this occurred when they managed to transcend their own self, with self-acceptance, and an assimilation that carried the self beyond identification with the disease. However, other positionings were detrimental, bringing an attachment to suffering — especially when the self-did not adapt to the new reality of physical and/or psychological losses.

Keywords: Breast Cancer. Grounded Theory. Experiences. Identity. Social Psychology.

ZUSAMMENFASSUNG

Die Studie umfasst eine qualitative Forschung, an der 15 brasilianische Frauen (zwischen 35 und 65 Jahren) und 12 deutsche Frauen (zwischen 50 und 81 Jahren) teilnahmen. Alle Frauen hatten sich einer Brustkrebsbehandlung unterzogen und ihre Diagnosen waren - zum Zeitpunkt der Führung eines einzigen Interviews mit jeder Einzelnen - in einem Zeitraum von 6 bis 24 Monaten erfolgt. Die zentrale Frage der Forschungsarbeit lautete: Welche sind die größten Herausforderungen für brasilianische und deutsche Frauen angesichts der Entdeckung und Behandlung von Brustkrebs? Ziel war es, interne Vergleiche zwischen den beiden befragten Zielgruppen anzustellen und anschließend externe Vergleiche heranzuziehen, bei denen die Erfahrungen der Frauen mit dieser Erkrankung in beiden Ländern berücksichtigt wurden. Die Ergebnisse der Studie, der die datengestützte Theoriebildung (Grounded Theory) als theoretisch-methodischer Ansatz zugrunde liegt, zeigen die Unterschiede bei der Diagnosestellung auf. In Brasilien erfolgte die Diagnosestellung überwiegend nach dem Zeitpunkt der Selbstuntersuchung der Brust und der selbst festgestellten Veränderung und in Deutschland, als die Frauen dem Einladungsschreiben zum Mammographie-Screening seitens der Krankenversicherung folgten. Die Offenlegung der Krankheit wurde ebenfalls untersucht und dabei erwiesen sich die Stigmata von Brustkrebs bei deutschen Frauen als größer als bei an Brustkrebs erkrankten brasilianischen Frauen. Ein weiterer wichtiger Faktor waren die Unterschiede zwischen den verordneten Behandlungen. In Brasilien erhielten alle Frauen eine Chemotherapie und nur zwei von ihnen haben sich einer Strahlentherapie unterzogen. In Deutschland wurden alle Frauen einer Strahlentherapie unterzogen und nur einem Drittel der Befragten wurde eine Chemotherapie ärztlich verschrieben. Darüber hinaus wurden in der Studie unterschiedliche Haltungen in Bezug auf die Identitäten gemäß dem symbolischen Interaktionismus und der Übereinstimmung mit der Sozialpsychologie festgestellt, welche in der dreiteiligen Arbeit eingehend erörtert werden. Schließlich wird davon ausgegangen, dass einige Haltungen der betroffenen Frauen in beiden Ländern ihnen zum Vorteil gereichte und eine gewisse Verringerung des Leidens zur Folge hatte; wenn sie eine Transzendenz des Selbst, Selbstakzeptanz und eine Assimilation erreichten, die das Selbst über die Identifikation mit der Krankheit hinaus transponierte. Andere Haltungen, jedoch, hatten Nachteile zur Folge und Anhaftung an das Leiden , insbesondere, wenn sich das Selbst nicht an die neue Realität des physischen und / oder psychischen Verlustes anpasste.

Schlüsselwörter: Brustkrebs. Datengestützte Theoriebildung. Erfahrungen. Identität. Sozialpsychologie.

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ABBREVIATIONS LIST

ABNT – Brazilian Association of Technical Standards
APA – American Psychological Association
AT - Therapeutic Accompaniment
CDIS - Ductal carcinoma in situ
CEP – Research Ethics Committee
CLIS - Lobular carcinoma in situ
CVA- Cerebrovascular Accident
DGP’s – German Psychological Society (Deutscher Gesellschaft für Psychologie)
ER – Ethical Guidelines (Ethische Richtlinien)
GBG – German Breast Group
GKV – Social Illness Insurance (Gesetzliche Krankenversicherung)
HDI – Human development Index
IBGE – Brazilian Institute of Geography and Statistics
INCA – National Cancer Institute José Alencar Gomes da Silva
INPS - National Institute of Social Security
IPSEMG - Minas Gerais State Social Security Institute
LGBTI+ - Lesbians, Gays, Bisexuals, Transsexuals, Transgenders and Intersexuals and more.
NBR – Brazilian Standard
NGO´s - Non-governmental Organizations
OPAS – Pan American Health Organization
Org. – Organizer / s
PUC Minas – Pontifical Catholic University of Minas Gerais
RKI – Robert Koch Institute (Robert Koch-Institut)
SUS – Unified Health System (Sistema Único de Saúde)
TCLE - Informed Consent Form (Termo de Consentimento Livre e Esclarecido)
TF - Grounded Theory
Trad. – Translator/s
UBS – Basic Health Unit (Unidade Básica de Saúde)
UNiA - University of Augsburg (Universität Augsburg)
UNIMED - National Confederation of Medical Cooperatives - Unimed do Brasil
WHO – World Health Organization
ZfKD – Center for the Registration of Cancer Data (Zentrum für Krebsregisterdaten)

SUMMARY

INTRODUCTION

1 INTRODUCTION

1.1 Breast cancer: knowing the disease and its stigmas

Breast cancer is a disease that consists of an uncontrolled multiplication of the cells of the breast that, once dysfunctional, develop into a tumor. There are many types of breast cancer; some develop fast, while others do not. The sick cells can proliferate from one or more parts within the mammary gland, which are: areola, nipple, milk ducts, lobes, and subcutaneous fat (INCA, 2019; Maluf, Buzaid & Varela, 2014).

There is not a single and specific cause that determines the appearance of cancer, but rather a set of reasons, such as: reproductive history; endocrine, behavioral, environmental, and emotional aspects; and genetic and inherited factors. Environmental and behavioral factors include obesity and post-menopausal weight gain, sedentarism, smoking, and alcohol abuse. Some of the aspects relating to the reproductive history of the patient are: early menarche (before the age of 12), nulliparity, first pregnancy after 30 years of age, not having breastfed, late menopause (after 55 years of age), use of hormonal contraceptives (estrogen-progesterone), and post-menopausal hormone replacement therapy (especially for more than five years). Among the genetic and inherited factors are a family background of ovarian cancer, multiple cases of breast cancer within the family, especially before 50 years of age, and a family history of breast cancer in men (INCA, 2001; Brazil, 2015a; RKI, 2014).

Since breast cancer is not a single disease, but a set of illness that have in common the presence of malignant cells emerging in mammary tissue (and multiplying in an inadequate and excessive manner), there are different names and classifications for these diseases. According to Maluf, Buzaid, and Varela (2014), it is not easy to know the exact time it takes for regular cells to become malignant. For example, a diagnosed tumor of 1 or 2 cm may have taken months or even years to develop.

The most common types of the disease are breast carcinomas in situ, which can be divided into ductal and lobular carcinoma. Another type is Paget’s disease of the breast, a specific form of the illness that compromises the papilla; for this reason, it is known as papillary carcinoma. The cellular characteristics of this form of cancer are very specific: it may have or may have not an underlying lesion, and the presence of this condition may or may not be palpable. When a biopsy reveals either an infiltrating ductal carcinoma (also known as invasive ductal carcinoma), which corresponds to 85% of the occurrences of breast cancer, or an infiltrating lobular carcinoma (known as invasive lobular carcinoma), which represents 10% of the cases, surgical procedures as well as radiotherapy and chemotherapy before or after surgery are always recommended (INCA, 2001; Maluf, Buzaid & Varela, 2014; INCA, 2019).

According to INCA (2001), the rarest forms of breast cancer include inflammatory carcinoma — a clinical form of mammary carcinoma that presents inflammatory symptoms such as erythema, cutaneous edemas, and “orange peel" skin. This disease has a poor prognosis and can evolve really fast; it does not present specific cell types but has subcutaneous and cutaneous neoplastic emboli. Bilateral breast cancer, either synchronous or asynchronous, is another. The synchronous form is detected simultaneously on both breasts and it can be operated as long as both sides are within the surgery criteria. In asynchronous cancer, tumors are discovered in each breast distinctly, and this can be a primary tumor or one that occurs because of metastasis. Mammary sarcoma is a low incidence cancer with a variety of biological behaviors, demanding different treatment approaches for each patient based on histology, disease evolution during the diagnostic phase, and other factors. There is also male breast cancer, a rare illness among the male population, with the same surgery criteria as female breast cancer. The main issue here concerns the lack of skin on men’s breasts, making surgery a difficult option, and often leading doctors to choose adjuvant treatments such as radiotherapy and chemotherapy.

The Sírio Libanês Hospital (2017) describes that the surgeries are considered the definitive treatment for breast cancer. These are divided into mastectomies, which are the complete removal of the breast, including skin, areola and nipple; adenectomy, which is the extraction of the entire glandular tissue, preserving the skin, areola and nipple; and segmental resection or quadrantectomy, which consists in removing the tumor and at least 2 cm beyond its border, including the peritumoral tissue and the pectoralis major muscle. This last procedure is very common in breast cancer treatment, especially when the tumors do not exceed 3 cm in length. Usually quadrantectomy is followed by selective axillary dissection to investigate contamination range. Last of all, there is lymph node dissection, where the axillary ganglia are removed to avoid recurrence of the tumor via axilla. This form of surgery is recommended when examination of the sentinel lymph nodes indicates the existence of neoplastic cells.

Chemotherapy, radiotherapy, or even hormonal therapy are considered adjuvant treatments as they are implemented after breast cancer surgery to destroy any new microscopic outbreaks or to prevent recurrence. The treatments mentioned above are also considered neoadjuvant when they are applied before the definitive surgical procedure, in order to reduce the size of the tumor and to make the surgery less invasive. Those treatments can also be implemented to evaluate the chemotherapeutic agents used against the tumor. The evaluations of treatments have indicated that chemotherapy both in adjuvant or neoadjuvant forms presents the same benefits for breast cancer healing, but in many occasions the neoadjuvant method can be the best choice when the tumors are extensive and have already contaminated the axillae (Maluf, Buzaid & Varela, 2014; INCA, 2019).

One complication that can occur is metastasis, when a cancer spreads from the primary site to other parts of the body. Metastasis may happen when cancer cells travel through the bloodstream or lymphatic vessels to other parts of the body. Many cancer cells that detach from the primary tumor die without causing any problems. However, some transfer to a different area of the body, where they begin to grow and form new tumors. (INCA, 2019; Maluf, Buzaid & Varela, 2014; RKI, 2016b).

The National Cancer Institute José Alencar Gomes da Silva (INCA) considers the most effective ways of detecting breast cancer are clinical breast examinations performed by a gynecologist or mastologist, or even by a professional nurse, as well as self-examination of the breasts, in which the woman herself can identify any changes and seek professional help. Complementary exams to confirm diagnosis are mammograms, biopsies, and breast ultrasounds (INCA, 2019; INCA, 2001).

A diagnosis of cancer interferes in all aspects of a woman’s life, due to the social stigma of the disease, seen as synonymous with death, and as something incurable. The diagnosis affects not only the sick person but also her daily life, her family, and closest friends, as there is a fear of the challenges that arise in the treatment of the disease, especially in more severe cases accompanied by radical surgeries. A classic study is “Illness as Metaphor” by Susan Sontag (2002), originally published in 1978. In this work, the author discusses, among other things, how doctors deal very differently with a diagnosis of cancer than they deal with heart disease, for example. Quite often the patient is not informed about her own illness, but rather the family, as if the sick person were unable to deal with that information.

For Sontag (2002), who also had cancer, it represents an invasive disease, which emerges without asking permission and secretly takes over the patient’s body. The perplexity about the disease is experienced by the patient and by those who are close to her. The author also affirms that many patients perceived a distancing from friends and family that inevitably feel like transgressions — what Sontag calls a violation of taboo — as if getting sick with cancer was something immoral or obscene. Even the name has an impact, since its origin, relating to crabs, to tentacles, reveals a certain horror with regard to the disease. Many people cannot say the word “cancer” due to the strength of its stigma. The author also discusses the punitive aspect of contemporary diseases: once it was tuberculosis, today it is cancer. While in ancient history disease was thought to express character, today character itself becomes the cause of the disease. Thus, Sontag draws attention to the danger of this perception that places the burden of the disease on the patient. The stigma that once surrounded tuberculosis now surrounds cancer, and the suggestion that a person is responsible for her own disease weakens the patient further.

When Ambrósio and Santos (2011) carried out investigative research with different relatives of women with breast cancer, the conclusions of their studies pointed to the need to observe not only the women affected by the disease but also their relatives, who may face different psychological problems at different stages of the treatment. This is due to the stigma of breast cancer, permeated by the intrinsic relationship of the disease with death, which once absorbed by both sick women and their relatives, brings the fear of finality to the family environment.

Alexias, Lavdas and Tzanakis (2015) conducted a study on the experience of women with breast cancer and mastectomy, and concluded that, once the threat to life is resolved, intense psychosocial processes are caused to woman who try to adapt to the new body image, creating a new concept for herself and her social identities, such as her role as mother, wife or others.

According to Charmaz (1995), diseases such as cancer, which brings significant losses to the body, threaten the integrity of the self. The self is not readily adapted to the body that has suffered changes, either by surgery or due to the treatments received. In addition to the disease threatening the sense of integrity between the self and the body, it is necessary to consider that it threatens the social integration of the one who falls ill. Goffman (1988) points out how this stigma can be debilitating, as any attribute socially identified with the disease can be used to exclude the sick person. In the case of breast cancer, in addition to the association of the disease with death, the lack of hair is the striking stigma by means of which the social identifies the disease and the sick woman.

1.2 An international public health issue

Breast cancer is the most common type of cancer for women around the world, and it is the main cause of death for this segment of the population. The World Health Organization

(WHO) considers cancer as a public health issue, as it is the second main cause of death due to disease around the globe, responsible for 6 million deaths annually (WHO, 2002). It is important to note that, in Brazil, the disease has both a high incidence and a high mortality rate. This is most likely due to tardy diagnoses, since there is a good prognosis for cure when detection occurs early on. (Brasil, 2014; Brasil, 2015a).

Porter (2009), Bray and collaborators (2012) have carried out international studies on the correlation between social-economic development and breast cancer occurrences, and they identified that the highest rates of the disease are found in high-income countries, in comparison to middle and low-income nations. However, the lowest breast cancer survival rates are found in low-income countries. On the other hand, authors Youlden and contributors (2012) noted that the higher survival rates of patients in high-income nations started in the last decades, due to the early detection of cancer and to the improvement of treatment techniques.

Cazap and collaborators (2008) point out that in Latin America a number of actions were implemented over the last two decades, such as improvement of *screening* techniques. However, not every country on the continent adopted these actions, and they did have not joined forces to create an organized program capable of gathering data based on populational studies. For Fayer, Guerra, Cintra e Bustamante-Teixeira (2016), this lack of systemization of actions is reflected in cancer survival rates: in Latin American countries this number is approximately 20% lower than the survival rate found in European countries and in the United States.

In Brazil, the Breast Cancer Control Information System (SISMAMA) was implemented in 2009. This system was created to standardize national data collection on the screening, diagnosis, and treatment of breast cancer, in order to improve actions for controlling the disease (Brazil, 2010). Nevertheless, Azevedo and Silva, and contributors (2014) criticized the results released until then by SISMAMA because, according to the authors, these results did not present data on the integration of actions, and were instead restricted to a description of the system and an estimate for coverage by region.

However, a document entitled “The situation of breast cancer in Brazil: a summary of data from the information systems” was published by INCA (2019), bringing new answers to society and to the scientific community. This data highlights regional differences in the disease incidence rates — higher in the South and Southeast and lower in the North and Northeast. Also, new correlations can be noted, such as a rise in the weight gain and general obesity of the population, as well as an increase in alcohol use, both risk factors for cancer. The study also noted an increase in the average age of Brazilian patients at the moment of the breast cancer diagnosis, shifting from 53 years of age in 2000 to 56 years in 2010. At the same time, there was an increase of 33.6% in breast cancer deaths in the country, with a total number of 16,069 deaths in 2016. Past records from 1980 to 2016 revealed variations in the number of deaths from 9.2 up to 12.4 per 100,000 women.

According to Breast Cancer Action (2012), this is the most common form of cancer among European women, with 350,000 new cases each year, and 130,000 deaths in Europe annually. Breast cancer is responsible for 26.5% of all cancer cases and for 17.5% of all cancer-related deaths among women. The highest rates of the disease are found in the Netherlands, Denmark, France, Belgium, and Sweden, and the lowest rates in Macedonia, Lithuania, Belarus and Latvia.

In the 1950s and the 1960s, a rise in deaths caused by breast cancer was noted in Europe. In some countries of Western Europe, mortality rates declined in the 1970s and in the 1980s; however, in a number of Eastern European countries there was an increase in deaths. There are major regional differences in Europe in terms of breast cancer survival rates. In Sweden, between the years of 1985 and 1989, 81% of diagnosed women who received treatment survived the disease, while in Slovakia and in Poland only 58% survived. There are also great discrepancies with regard to therapeutic procedures; in England for example, 65% of patients are submitted to conservative surgery that preserves the whole breast or parts of it; in France, that number is 57%, while in Spain, 13%, and in Estonia, only 8% of women have that type of surgery (Breast Cancer Action, 2012).

In Germany, nearly 1 in 8 women are diagnosed with breast cancer. Almost 3 in 10 women affected are 55 years old or less at the moment of diagnosis. According to Robert Koch Institute the rates are stable and have not increased in the last years. This is due to the introduction of breast cancer screening via mammography between 2005 and 2009 in every single state of the country. The increase and stabilization of this screening program has also led to a more precise identification of statistics about the incidence of the disease in Germany. There was also a significant increase of the survival chances of affected women due to the advances in therapy (RKI, 2017a).

The incidence rate for the disease in Germany is in the mid-range among the comparative studies that have been carried out in Europe. However, in this country 17,500 women perish per year because of breast cancer. In Belgium, France, and Denmark there is a higher probability of the disease; in the Baltic countries of Estonia, Latvia, and Lithuania, as well as in the southern countries such as Spain, Greece, and Portugal the incidence rates are significant lower (Breast Cancer Action, 2012).

Bray and collaborators (2018) used the estimates of GLOBOCAN 2018 for cancer incidence and death rates, produced by the International Agency for Research on Cancer, to analyze the data of 36 different types of cancer in 185 countries of the world. The authors noted that breast cancer is the most common disease among women from almost every population of the planet. There were approximately 2.1 million new cases registered in the global population in 2018, causing around 627 thousand deaths of women.

1.3 Brief contextualization about health services in Brazil and Germany

In Brazil, the National Cancer Institute José Alencar Gomes da Silva (INCA) is the government agency responsible for cancer records and monitoring. INCA is nearly 80 years old and is currently linked to the Ministry of Health, and therefore the Unified Health System (SUS), a public policy that structures the provision of health care services for the Brazilian population (INCA, 2017). The Institute presents itself as the most complete organization in the country regarding cancer control, with the objectives of assistance, prevention and early detection of the disease, epidemiological surveillance, education, and research.

The document prepared by INCA (2017) points out the most common types of cancer in Brazilian women in terms of new annual cases, excluding skin cancer (non-melanoma[1] skin tumors) : in first place is breast cancer, with 59,700 cases; in second place is colon and rectal cancer, with 18,980 cases; in third place is cervical cancer, with 16,370 cases; cancer of the trachea, bronchus, and lung appear in fourth, with 12,530 cases; and in fifth place is thyroid cancer, with 8,040 cases. According to the document, breast cancer leads the estimates for the female population when analyzed in isolation, and its highest incidence is found in the most developed regions of the country, accounting for 25% of new annual cases of the disease.

The Robert Koch Institute (RKI, 2016a) is around 240 years old; it was founded in Germany in 1891 and is currently part of the Federal Ministry of Health, working with the national “Zentrum für Krebsregisterdaten” (ZfKD) — Data Record Center for Cancer. RKI presents itself as the main scientific and medical institution belonging to the federal government of Germany, and its goals are public health in its many aspects. The Institute’s

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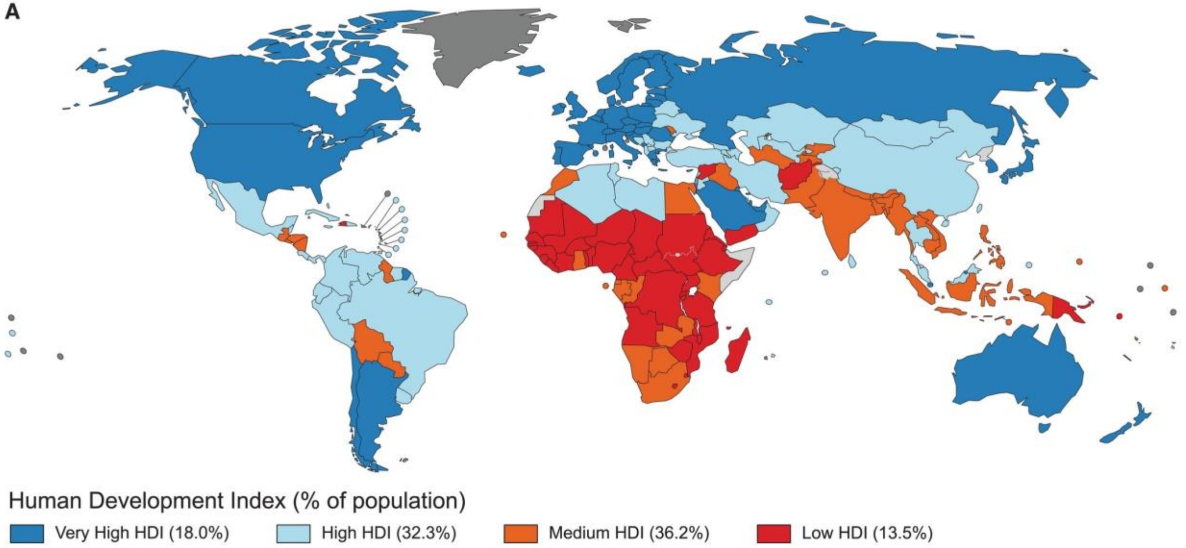
[1] INCA (2017) affirms that numbers for non-melanoma skin cancer are difficult to estimate, even though it has the highest incidence among cancer types, because not all databanks register these cases. This type of cancer is very common due to factors like excessive exposure to UV radiation and specific characteristics such as light skin, eyes, and hair color, besides a family or personal history of skin cancer.

main responsibilities are to combat infectious diseases; analyze health trends for the population; and develop scientific methods for investigating suspected cases of intentionally disseminated pathogens. According to RKI (2016a), almost 500,000 men and women are diagnosed with malignant tumors each year, which can be associated both with an aging population and with advances in the medical care offered in the country.

According to RKI (2017a), the order of new yearly cases of disease incidence in German women, excluding non-melanoma skin cancer, is distributed as follows: first is breast cancer, with 69,220 cases; next is bowel cancer with 27,890 cases; third is lung cancer with 19,280 cases; fourth is uterine cancer with 10,680 cases; and in fifth place — just as with men — is malignant melanoma skin cancer, with 10,310 cases recorded among German women in 2014 (RKI, 2017a).

Bray and collaborators (2018) note that cancer incidence and mortality is growing rapidly worldwide, and although the reasons for this are complex, the phenomenon is associated with population aging and growth. These bring changes in the prevalence and distribution of the main risk factors to the emergence of diseases, several of which are associated with the socioeconomic development of countries. The studies that the authors carried out using GLOBOCAN 2018 reveal that cancer is the biggest cause of premature death in the wealthiest countries of the planet. This points to the impact of national levels of social and economic development on lifestyle, and consequently on the emergence of non-communicable diseases, such as cancer (Bray, 2018).

Image 1 - Human Development Index (HDI) in Different Regions of the World



Source: Adapted from Bray and collaborators (2018). Originally created by the United Nations Procurement Division/United Nations Development Programme (Bray et al., 2018, p. 396, picture 2).

As can be seen in image 1, Germany is a European country that holds one of the highest levels of Human Development Index (Very High HDI — in dark blue) in the world. On the other hand, Brazil, a Latin American country, has a high Human Development Index (High HDI — in light blue). The other two levels noted on the map represent countries or regions of the world (especially in Africa and Southern Asia) that have a lower Human Development Index (the orange color stands for Medium HDI and the red for Low HDI).

However, although both of these countries, as discussed previously, share a high incidence of breast cancer, there are vast social, economic, and demographic differences between them. Brazil is a relatively young country and yet it has more than double the population of Germany. Indeed, *"Brazil has reached 210.1 million inhabitants in 2019, according to IBGE (The Brazilian Institute of Geography and Statistics) data"* (UOL, 2019, p.1). The Brazilian territory has an area of 8,514,876 km², and it is the 5th largest country in the world in territorial extension. It only stands behind Russia, Canada, United States, and China. *"The broad territorial area of Brazil means this country is considered to have 'continental dimensions', as it is almost the same size as Oceania (8,525,989 km²) and is a little smaller than the entirety of Europe (10,180,000 km²)"* (Mundo Educação, 2019, p.1). Germany, on the other hand, has a population of 83 million people and it is the most populous country in the European Union. That is mainly due to immigration and not because of birth rate, which is low when compared to other countries in the world and lower than the death rate for the country. Germany has a small territorial dimension of 357 thousand km²; however, its location in the center of the European continent, as well as its economic wealth, makes the country attractive to immigrants (Deutsche Welle, 2019).

To discuss health service provision in both countries it is necessary to make some considerations about the history of each one. According to Fernandes, Rocha, and Frazão (2014) it is not an easy task to depict the history of public health in Brazil. There was a complex colonization system, exposing the indigenous population of the "discovered lands" to diseases never known before and leading to a sharp drop in that population. Colonization also brought Black people from several locations in Africa and, after that disastrous period of slavery, an influx of European immigrants seeking employment on the vast farms across the territories that would later form the Federative Republic of Brazil. This major populational movement in a "young" and tropical country was not insignificant in terms of the health history of the current population. Many diseases spread throughout the country, and many discussions were held about what should be assisted in the public rather than the private services. However, it is undeniable that Brazil has made progress since its early days, when it was a colony of Portugal, and from the first years of the Republic until the current days.

Duarte, Eble, and Garcia (2018) note the anniversary of the "30 years of the Unified Health System" and the importance of SUS to the Brazilian citizens. The authors state that *"with the creation of SUS by the promulgation of the Federal Constitution in 1988, Brazil became the largest country in the world with a public health system based on the principles of universality, equity, and integrality."* (Duarte, Eble & Garcia, 2018, p. 1). The universal nature of SUS covers actions of public health surveillance throughout the whole Brazilian territory, and is also responsible for the national immunization calendar, which gives all citizens access to the immunobiological vaccinations recommended by the WHO. In terms of equity, SUS provides health actions and services to the population, with nearly 80% of Brazilians depending exclusively on SUS for health care. The users of private health plans also turn to SUS for high complexity treatments or to obtain high cost medication. In the current Brazilian scenario marked by political crises, the unemployment rate is on the rise, which implies that fewer and fewer citizens may be able to afford private health plans. The health assistance offered by SUS is integral, attending to all the health needs of the Brazilian population.

Paim (2018) argued that SUS is not yet fully consolidated, and it runs the risk of being dismantled with the political crisis that began in Brazil in 2014. According to the author, *"Since 2014, the capital coup woven by the media, segments of the middle class, and the Parliament, with support from the Judiciary, has broken the social pact that was established at the end of the dictatorship, attacking democracy and suppressing a whole range of civil, social, and political rights."* (Paim, 2018, p. 1724). After this point, SUS has ceased to be a priority for the federal government in Brazil and has suffered many attacks such as the restriction and freezing of funds directed to health care. That complicates the entire operating system in the federal, state, and municipal spheres. Additionally, the author notes the strong opposition to SUS by private health care providers (Supplementary Health Care) and by the pharmaceutical and medical equipment industries.

According to Vilarinho (2010), who analyzed the relationship between public health care and private services, Supplementary Health Care includes private health services as well as a variety of hospitals and clinics which may or may not be linked to SUS. Public health care has its own network. However, it also establishes partnerships with private health services. The author's research indicates a certain dominance of the public authority, where political interests prevail in matters that concern private services, such as third-party health providers working for SUS. From this perspective, supplementary health care continues to grow, and is especially harmful to the rights of private health care users, as well as strengthening a form of corporativism with those who are in power in order to favor the private health care companies. Therefore, it is also detrimental to those who depend on SUS, since poverty in Brazil continues to grow, while public accounts are badly administered.

Breast cancer treatments in Brazil are offered by SUS, and they can be classified under the following strategies of care: primary health care, including prevention and detection by a general practitioner or gynecologist; moderate complexity treatment, offering services that investigate suspicions and formulate a diagnosis, including exams and mastology consultations; and high complexity treatment in a reference hospital with oncologists and a professional team within the oncology department (INCA, 2019). The women who have access to private health plans and services most of the time go straight from gynecologist to mammogram, and then seek treatment in private oncology hospitals. However, all Brazilian women may always turn to SUS and its strategies of care to receive cancer treatment.

In Germany, health services are mainly offered by statutory health insurance companies. The origins of the German social State date to the end of the 19th century and to Otto von Bismarck, who introduced the idea of social security to Germany in 1883 (Giovanella, 1998; Giovanella & Stegmüller, 2014; Das Gesundheitssystem kennen lernen, 2015). Although Bismark was motivated by political interests, he laid the foundations for what Germany has today in terms of modern social welfare (Das Gesundheitssystem kennen lernen, 2015).

The three key principles of social security rely on the first paragraph of Article 20 of the Basic Law, and they are: principle of Security; principle of Care; and principle of Provision. The first one regulates social risks, while the second includes social care and assistance for all those who need them. Finally, there is the legal claim of the principle of Provision, securing public supplies by means of fees and taxes (Das Gesundheitssystem kennen lernen, 2015).

Still according to Das Gesundheitssystem kennen lernen (2015), it is the role of the Federal Ministry of Health: to exercise supreme authority over the entire health system of the Federal Republic of Germany; to monitor the Federal Joint Committee, the National Association of Statutory Health Insurance Physicians, and the Central Federal Association of Health Insurance; to compile the accountability, legal decrees, and the administrative regulation of health insurance, social security, and admission to professions in the health area, as well as to ensure the protection of health and the reliability of medication and medical devices.

Nearly 90% of German citizens are linked to a state health insurance, which covers children and spouses without charge via a family insurance policy. Only 5% of Germans use private health insurance, with 2% using other providers, and around 3% of Germans do not have insurance at all. Therefore, those using state health insurance, which are statutory health insurance companies that fulfill the duties of the State regarding health care assistance, make up the majority of the population. Those with private insurances work with commercial companies connected to business — this means they are required to earn an annual income that is over an amount predetermined by the government. Other forms of insurance are mostly aimed at the beneficiaries of social welfare, but are also offered to, for example, the spouses and children of certain professional groups such as police officers and federal employees. Both public and private health insurances cover the costs of medication as long as they are prescribed by physicians and do not have merely aesthetic purposes. Patients pay a minimum fee predetermined at the moment of purchase, no matter the value of the medication, and the rest of the cost is covered by their health insurance (Das Gesundheitssystem kennen lernen, 2015).

According to Ferreira and Mendes (2018), in 2008 Germany promoted two important changes that impacted health insurance rights. The first was to implement mandatory affiliation of all citizens to health insurance providers. The second was to ban anyone over 55 years of age from returning to public health insurance after having opted for private insurance. The authors also note that, in comparison to other European countries, there is an explicit commercialization of health services in Germany, with a prevalence of private health institutions in the country.

How does the health system operate in practice? The statutory health insurance companies collect collaborator contributions (employee/employer; pensioners/social welfare), which are fixed fees applied to the worker’s gross salary; these resources are managed in a so-called “health fund”, and this forms the basis of the mandatory health insurance. Initially, the firms count only on the additional contributions of their members but depending on the circumstances they can activate the health fund of the *Gesetzliche Krankenversicherung* (GKV - Social Illness Insurance) to aid with expenses. The companies receive a basic monthly fixed fee per person insured that varies according to age and morbidity (this morbidity rate is calculated by considering the client’s history — serious diseases, accidents that led to disability, etc.). As an example, it was reported that health expenses in 2013 reached 314,939,000 Euros in Germany. Those expenses were divided as follows: the Statutory Health Insurance paid for 57.6%, the families contributed 13.6%, social welfare insurance donated 7.7%, 4.6% of resources came from public budgets, 4.3% from employers, 1.6% from social accident insurance, and 1.4% from public retirement insurance (Das Gesundheitssystem kennen lernen, 2015).

Giovanella and Stegmüller (2014) discuss the organization of health service provision in Germany and note that there is no established first, second, or third level of care. Health professionals are self-employed, working out of private offices linked to GKV via the National Association of Statutory Health Insurance Physicians. Therefore, there are no primary, secondary, or tertiary teams for health care. However, there are general and specialist practitioners as well as clinics and hospitals, which are always linked to GKV and offer health care services according to the complexity level they are qualified to provide.

Regarding breast cancer, Germany has been remarkably efficient in *screening* the disease by means of mammography, according to parameters established by the WHO. The level 3 guideline, as the program is known, puts mammography in a central position in the fight against the disease and promotes and shares scientific researches about this theme (Schultz, Kreinberg & Fischer, 2003; Albert, Altland & Duda, 2008).

Albert, Altland, and Duda (2008) point out that German women are highly aware and responsive to health insurance campaigns for mammograms, which improved cancer screening in the country. According to the authors, there was a significant advance in terms of early discovery of the disease, raising chances of cure and decreasing treatment costs.

1.4 Research issues and objectives

Breast cancer is a disease with a series of implications, touching on body aesthetics, sexuality, and personal and family life, besides causing impact on public or private health care systems due to its high incidence. It is a disease that has led to the formulation of a variety of discursive practices, revealing continuous or discontinuous concepts, and pointing out reflective categories, normative rules, and several other institutionalized ideas that deserve investigation. The issue that served as a starting point for the study was: what are the main challenges faced by Brazilian and German women during the discovery and treatment of breast cancer?

To answer this question the following methodological objectives were established: a) to conduct semi-directed interviews with women experiencing breast cancer in both Germany and Brazil; b) to identify similarities and differences in the process of fighting the disease for the two audiences surveyed, comparing them internally and subsequently with each other. In addition, some of theoretical objectives were also established, such as: c) to research the literature that addresses the treatment and experiences of women who had breast cancer; d) to present Grounded Theory as a methodological tool for the analysis of qualitative research.

1.5 Methodology and Study Characterization

In Brazil, the study was carried out with women undergoing treatment for breast cancer linked to CETUS Oncology, an outpatient hospital that serves private patients, health insurance companies, and SUS, performing exams and procedures for cancer treatment. The institution is located in the metropolitan region of Belo Horizonte in the state of Minas Gerais, in Brazil's Southeast, one of the most developed regions of the country along with the South. CETUS consented and agreed to support this study, as can be seen in Appendix A, referring women patients for the interviews.

In Germany, the study was conducted with women undergoing breast cancer treatments at the Kliniken Ostallgäu-Kaufbeuren, a regional hospital located in Bavaria, in Southern Germany. The institution gave its consent and support to carry out the research as shown in Appendix B, referring women patients to be interviewed. According to the hospital's website, this is a level II clinical center, and counts on two other level I clinics to offer national care in the most diverse medical disciplines. Kaufbeuren is the heart of this network of clinics, with close to 20,000 patients hospitalized annually and around 45,000 patients receiving ambulatory treatments (Klinikum Kaufbeuren, 2019).

The project to carry out the study has met the criteria required for conducting research involving human beings in Brazil, as directed by resolution 466 of 2012 — CNS 466/12 of the National Health Council - of the Ministry of Health (2012). The project was also approved by the Ethics Committee on Research of PUC Minas, under evaluation number 1,906,726 from February 3rd, 2017 as can be found in Appendix C.

Fifteen (15) Brazilian women with breast cancer participated in the study, randomly chosen by the CETUS Oncology Day Hospital, that supported the research in Brazil. All the women signed a consent form, according to the model available in Appendix D. This part of the study took place in Brazil between April and August of 2017. The exclusion criteria for participation in the research in both countries were: cancer detected at an incurable stage, receiving only palliative care; pregnancy; presence of clinically detected neurological problems; and submission to psychiatric treatment prior to cancer diagnosis. In addition, time of diagnosis was a consideration for inclusion in the study — in order to study women still undergoing treatment, diagnosis should have taken place between 6 (six) and 24 (twenty-four) months prior to the study. The methodological approach sought a group of participants who were not dealing directly with death or dealing with other psychiatric implications that could harm them if they were included in the study.

The participants of the German study were 12 (twelve) women, also chosen at random by Klinikum Kaufbeuren. In line with ethical guidelines promulgated by the Declaration of Helsinki (World Medical Association, 2014), they also signed an informed consent, according to the model in the Appendix E, giving their permission to participate in the study. This stage of the research process took place in Germany between April and November of 2019.

Each participant was interviewed in a single meeting and a semi-structured interview script was used as a guide for the conversation. Other questions that emerged during the interview were also included in the study. Each interview lasted an average of 50 minutes. The researcher also used the records made in her field diary to better understand the phenomena studied. According to Laperrière (2010), the use of fieldnotes permits the researcher to intensify their reflexivity. This instrument allows for a better understanding of the research field, its diversity, and its procedures, in addition to supporting successive hypotheses by means of data triangulation. Appendix F contains the script for interviews with Brazilian women, while Appendix G contains the script for interviews with German women. The latter was adapted to the German language and adjusted to take into account socioeconomic criteria for the country's population. However, it preserved the essence of the questions and the context of the study.

A form with treatment data such as time of diagnosis, stage of cancer, and therapies used also served as a recording instrument. In Brazil, this form was completed through the survey of medical records and prescriptions. In the term signed by the Brazilian participants, authorization was given for access to medical records. The form was complemented by means of direct questions after the interview itself, and the answers were compared to the data found in the medical records. The model of the form used for the study in Brazil is in Appendix H. In Germany, the form was completed via the data recorded in a small booklet carried by each German woman, called *Nachsogerkalendar* — a records tool adopted in the country to monitor all treatments undertaken. The model for the data sheet used in Germany is in Appendix I.

The interviews were recorded on audio, in the respective language of each country. Subsequently the audio was transcribed and, in the case of the German interviews, meticulously translated into Portuguese before analysis. The analysis was based on Grounded Theory in accordance with Charmaz's proposal (2009), with a thorough line-by-line investigation of the transcriptions in order to build the thesis originating from the study. Next, a continuous comparative process was initiated, with the grouping of participants by socioeconomic conditions, leading to a detailed analysis of the phenomena. In this stage, the *"six Cs: Causes, Contexts, Contingencies, Consequences, Covariance and Conditions"* (Glaser apud Charmaz, 2009, p. 94) connected the studies to specific theoretical codes that emerged from the research data. After this, these theoretical codes were grouped by categories, compared with each other, reorganized, and reanalyzed, until the studied experience could be presented by means of new theoretical statements. Then, women's experiences were compared to each other, in each country, culminating in a text on the process for Brazilian women and another for German women. The outcome was to compare the central issues that emerged in each group in order to conclude the study.

1.6 Grounded Theory: a brief revision of literature

According to Berterö (2012), there is a debate in Social Sciences on the nature of Grounded Theory (GT), and the author's detailed examination of work of other researchers has pointed to a wide range of approaches within the same nomenclature. Glaser and Strauss, with "The Discovery of Grounded Theory: strategies for qualitative research", are mentioned by Berterö (2012) as the first in this branch, offering a methodological consensus and systematic strategies for the practice of qualitative research.

The defining characteristics of GT include: simultaneous involvement in data collection and analysis, construction of analytical codes and data categories, use of the constant comparison method, development of theory during each stage of data collection and analysis, drafting of notes/memos in order to elaborate categories, non-representative sampling of theory construction, and, finally, revision of literature after completion of theory analysis and development. Another key aspect of GT is its focus on a specific issue, from which categories are developed, based on a central or nuclear idea — called a core category by those who embrace this approach. (Berterö, 2012; Charmaz, 2009, Porter & Welch, 2018).

Both Tarozzi (2011) and Keller (2013) state that GT is a technique for carrying out social research that focuses on the systemization of researched data, created initially by Glaser and Strauss who wrote about the experience with death in American hospitals in the 1960s. Tarozzi (2011) further explains that Glaser and Strauss aimed to introduce a style of empirical research that was not centered on testing hypotheses, instead focusing on the empirical reality of the research subjects. They pinpointed two types of theory: formal, with a wide range of disciplines, centering around generalization; and substantive, focused on the comprehension of social life, applied within the limits of a given social context. Thus, substantive theory was the type adopted by them, in a form of textual construction based on the very terms and concepts that social subjects use when describing their experiences.

Anselm Strauss and Juliet Corbin (2008) published “Techniques and Procedures for Developing Grounded Theory”, which identifies a path that seeks to understand the symbolic nature of the social agent’s experience. For both Tarozzi (2011) and Berterö (2012), a split occurred between Glaser and Strauss when the latter began working with Corbin, leading to a modification of the initial proposal for GT. Strauss and Corbin (2008) stipulate the search for previous tools for analysis, assuming that a complexity exists that involves the observed phenomenon, and leading to the emergence of a previous interpretative role for the data. Glaser, on the other hand, maintains a firm stance regarding the methodology that began GT, focusing largely on objective empiricism. (Tarozzi, 2011). Finally, a third line of thought regarding GT emerges, linked to Charmaz, conducting studies from a constructivist perspective. (Tarozzi, 2011; Porter & Welch, 2018).

Glaser’s grounded theory, sometimes called Classic Grounded Theory, has from the start been supported by empirical production, from which the terms and concepts were taken and interpreted, giving way to a theoretical consensus. Some 20 years later, with Corbin as co-author, Strauss would lead grounded theory in the direction of verification and of what became known as Straussian Grounded Theory. (Tarozzi, 2011; Charmaz, 2009; Porter & Welch, 2018).

Berterö (2012) explains that, in the 1990s, GT was criticized for its positivist premises, gaining acceptance from quantitative researchers. However, some researchers moved away from the positivism of Glaser’s and Strauss’ grounded theory, as did Charmaz, who exchanged conceptual theory, where she began her studies, for grounded theory, bringing a constructivist sense to this approach. Charmaz, cited by Berterö (2012), maintained most of the defining characteristics of GT, adopting, however, a more subjective and reflexive posture. The results of constructivist grounded theory, including its categories, are presented as a narrative, and not as a rigid theory, extracted purely from the discourse of social actors without reflecting upon the subjectivity within which they position themselves. In turn, Charmaz (2009) herself clarifies which are the constructivist aspects of her GT, and how researchers should employ the theory in order to work with multiple objectives and with the analytical focus points that emerge throughout the process. For the author:

> Interpretative theorization results from social constructivist suppositions that permeate symbolic interactionism, ethnomethodology, cultural studies, phenomenological discourse, and narrative analysis. This theorization is not limited to individual actors or micro situations. Nor should it be. On the contrary, interpretative theorization can go beyond individual situations and immediate interactions. (Charmaz, 2009, p.176)

Clarke gave grounded theory a new direction, including notions of feminism and post-structuralism, in order to create a fusion with these concepts. (Clarke, 2005). The author assimilated influences from symbolic interactionism, as well as constructivism, as did Charmaz, incorporating these into a sort of theoretical fusion. According to Berterö (2012), Clarke presents a situational analysis for advocates of GT.

There is a method to ensure GT. Nevertheless, this takes into consideration the many directions that must share a common ground. Simultaneous involvement in the gathering and analysis of data is essential in order to guarantee the paths of GT, which rejects the simple gathering data followed by subsequent analysis. Researchers should avail themselves of key techniques such as theoretical saturation, hierarchical coding, and processes, in order to identify a core category. However, the philosophical, epistemological, and methodological approaches may vary according to the researcher’s choices. (Berterö, 2012; Charmaz, 2009)

In this research, I focused on the approach proposed by Charmaz (2009) in “Constructing Grounded Theory”. The author has a number of studies in which GT is used as a theoretical-methodological approach, investigating, and discoursing on the experience of people with chronic disease (Charmaz, 1990; 1995; 1997), which prompted my interest in the author’s work.

The reach of data after interviews are concluded is an important factor in constructing work that falls in line with GT. For instance, to understand the experiences of social actors with a chronic disease such as cancer, it is necessary to analyze what sick people say about how they found out they had the disease — a different issue from the simple obtainment of a diagnosis. For this, the researcher must be attentive, ready to take questioning further in the case of incomplete answers. This is not always necessary, as some participants describe their experiences with greater mastery. *“An interview is contextual and negotiated. Whether the participants narrate their own stories without interruption, or whether researchers request* *specific information, the result is the construction or reconstruction of a reality.”* (Charmaz, 2009, p.48)

Coding is a different stage, taking place after data has been transcribed. It is important for the researcher to set their ideals aside, seeking to forget what they had in mind when creating the questions. This is a strategy that permits an immersion into the narrative aspects of the participants, allowing those analyzing the data to identify *in vivo* the codes with which the experiences have been told. Thus, the phrases that contemplate these experiences are taken up again as we attempt to understand into which category they fit. *“The oldest rules of grounded theory prescribe carrying out the initial coding without bearing in mind preestablished concepts.”* (Glaser, 1978 apud Charmaz, 2009, p. 74)

For Charmaz (2009), the process of coding promotes links between the data and the development of a theory that emerges from it, and returns to it, aiming at explaining this data. For this to occur, the researcher must debate with the data, seeking to understand to which categories it connects. In this stage, the data begins to be differentiated, defining a focused coding that *“demands that decisions be made about which of the initial codes allow a better analytical comprehension to categorize the data in an incisive and complete manner.”* (Charmaz, 2009, p. 87) Later, the researcher, using constant comparative methods that take into account the reports of the participants as being similar or distinct, finds themselves facing axial coding, which *“relates categories to the subcategories, specifies the properties and the dimensions of a category, and regroups the data that you have fragmented during the initial coding to bring coherence to the emerging analysis.”* (Charmaz, 2009, p. 91)

After carrying out a number of analyses, the researcher must then write memorandums; primary texts that that should define how the material contemplates ideas about a possible theory that explains the investigated phenomenon. At times, it may be necessary to return to the field of research to clarify new ideas that emerge from the material gathered. After this, the memorandums can begin to reflect the creation of the theory. (Charmaz, 2009)

Every GT process demands a form of abductive thought, within which theoretical conjectures are elaborated. These conjectures should then be verified, once more, by means of continuous comparisons, depending on the themes and aims of the researcher. According to Charmaz (2009), within the field of Social Sciences the themes and aims include, among others: Individual and collective actions; Choices and restrictions; Meanings and actions; Points of view and differences; Social positions and networks; Power and influence; Opportunities and inequalities; Moral life, moral action, and moral responsibility.

1.7 Outline and Structure of the Dissertation

The first part of this dissertation is focused on the study carried out in Brazil, with the experiences of the Brazilian participants analyzed and described in chapters and subchapters that lead to a Thesis based on these investigations, specific to this group of participants. This section opens with an introduction to the socioeconomic context that encompasses the women who took part in the study, followed by an analysis of the discovery of a diagnosis, of how the news was shared, and of the construction of support networks. Next is a description of the treatments these women were subjected to, and of how they experienced the different stages of the processes in the fight against breast cancer, which brought physical losses such as alopecia, weight changes, and psychological changes such as mood swings and others. A few exceptional situations that took place alongside the illness are highlighted, such as a pregnancy and two divorces. Finally, this section looks at common strategies for facing adversity, as well as notions about the body and their significance, all of which had a direct relationship to the positioning of the women, who had to rethink some of their choices in order to overcome the disease – in the first Thesis of this work.

The second part of this dissertation introduces the study and data analysis for the German women. Following the same objectives, in this section the researcher first contextualizes the participants' socioeconomic conditions, followed by how they discovered they had breast cancer, and which treatments the women went through. Next, the main challenges the women faced are described, along with which subjective changes they had to make so as to overcome the losses that stemmed from the disease. Last of all is the Thesis, constructed with basis on the direction that emerged from the analysis of the women's reports, taking into consideration their identities, which were strongly connected to domestic and paid work, as well as their positioning, their choices, and that which they were forced to surrender.

Finally, in the third part of the study, comparisons are made between how the Brazilian and German women dealt with breast cancer, taking into account their experiences regarding diagnosis discovery, their main challenges, and the treatment procedures, paying specific attention to chemotherapy, which was prescribed for all the Latin American women. In this section, the differences in positioning and concepts are discussed, in terms of their connections with the social environment, forming the basis for the third Thesis of this dissertation.

PART I

2 PART I: RESEARCH IN BRAZIL

Following the guidelines of Charmaz (2009), the data was analyzed line by line, initially identifying the predominant codes within the interviews in order to verify the presence of these in the majority of participant reports, and aiming at reaching saturation in the processes of constant comparison. For instance, to work with the categories that were later named "discovery of diagnosis" and "establishing a diagnosis", the following codes were taken into consideration: nodule, lump, bump, breast deformity, breast secretion, and other similar terms. With these codes, a new correlation was made, adding other codes such as: routine appointment, mammogram, doctor/s, self-exam. Thus, it was possible to regard the above-mentioned categories and identify connected questions that spanned from time of diagnosis to emotions, and other aspects within these contexts, all associated to the discovery of the disease, besides observing socioeconomic issues. Based on this, the researcher created memorandums, comparing them and listing their importance in representing the experiences of the women who participated in the study; this led to the final texts that make up this stage of results and discussions. In the same manner, the other categories were also "created" and, at the end of all the analyses, the best form of textual presentation was chosen.

Other aspects were taken into consideration, such as constant readings of other studies associated with breast cancer, based or not on GT, both in order to search for new ideas, and to better understand the phenomena that emerged during the data analysis process. Throughout the work, the authors whose studies corroborate with this research are cited.

An aspect noted during the process of analyzing the interviews with the Brazilian participants was the possibility of observing the momentary identity choices made while facing cancer. The work of Charmaz (1995) contributed immensely to this process, as well as Charmaz (1990; 1997; 2009; 2014; 2015). As described by Strauss (2009) in "Mirrors and Masks: The Search for Identity", the central discussion about identity passes through language — the manner in which people speak, write, listen, interpret, and respond during social interaction, bringing forth aspects of identity such as the belonging to certain social groups, or the not-belonging to others. An analysis of these phenomena depends on the perspicacity of the researcher, who must be capable of comprehending the complexity and fluidity of the collective and individual aspects that interlink to form identity.

2.1 An introduction of the socioeconomic issues of the women who participated in the Brazilian study

Fifteen Brazilian women took part in this stage of the research, ranging between 35 and 65 years of age, from different social classes and distinct socioeconomic situations. The participants were all attending an outpatient clinic, the CETUS Oncology Day Hospital for cancer treatments. This clinic attends private patients, health insurance clients, and patients from the national public health care program, the Brazilian Unified Health System (Sistema Único de Saúde — SUS). The emphasis of this private hospital is on carrying out exams and procedures to treat different types of cancer. The institution is in the metropolitan area of Belo Horizonte, Minas Gerais, and took a proactive stance regarding this research, contributing with the selection and referral of participants for the interview process. The women, in turn, were contacted by the researcher and agreed to participation in the study, signing consent forms and receiving the researcher in their homes, where a single interview was carried out with each one. The women lived in different municipalities; however, all were located within the Belo Horizonte metropolitan area.

The list of patients was created by a nurse at CETUS Oncology Day Hospital who helped select the women for the study according to the previously mentioned inclusion criteria. She was also responsible for notifying the women that they would be contacted by the researcher. Despite this, the first question most participants asked during the initial phone contact was: “You’re the lady who’s going to interview me because I have cancer, right? But why was I chosen again?” This pointed to an emergence of fear, as if being nominated as a participant for a study could be a cover for something secret and negative. Thus, it was necessary to handle this mistrust with caution and respect, so that the interview meeting could take place without posing a threat to the women. Of the 18 (eighteen) women selected and contacted, only 3 (three) declined participation, with 2 (two) of these alleging lack of time and a busy schedule due to treatments, and the other stating she had no interest in speaking of the subject with anyone. It is important to note that, already in the first phone contact, most participants began immediately talking about the discovery of the disease, in other words, how they found out about the diagnosis.

Table 1 summarizes the socioeconomic data of the participants, bringing up maternity, profession, and other relevant aspects that characterize the women in the Brazilian part of the study. In terms of schooling, only 2 (two) of the women had completed college and post-graduate education, while another, at the time, was studying for her bachelor’s degree. Of the remaining women, 6 (six) had completed high school, 3 (three) had completed elementary education levels, and 3 (three) had only taken the first few years of elementary school. These latter women can be considered as having a precarious level of schooling.

There was a variety of professions. One of the two graduates, one was an independent entrepreneur, according to her area of training, and the other was a social worker — an occupation that also requires a college education. Some of the women were government employees (all of these had completed high school), while others with this same level of schooling worked in the private sector, for instance, in commerce or in secretarial jobs. Others with complete or incomplete elementary schooling had more labor-intensive jobs in the private services sector, such as production operator or carrying out general cleaning services. 2 (two) of the women declared their occupation as homemakers, one of whom was retired. And 1 (one) had retired after working as a housemaid. Regarding family income, 4 (four) of the women lived on 5 or more times the minimum wage, 4 (four) had a family income between 3 and 4 minimum wages, and 7 (seven) women had a family income between 1 and 2 minimum wages.

In terms of maternity and family group, 13 (thirteen) women had children and only 2 (two) did not. The families were for the most part made up by the woman and her husband and offspring (with ages that ranged from children all the way up to youths). Only one woman lived completely on her own, as she was single, and her daughter lived in another city. The older participant, a widower, had two young adult grandsons living with her. Another woman, single and childless, lived with a niece and her niece’s family.

To maintain the privacy of each participant, all names have been changed and the women were divided into three groups: A, B, and C, according to the initials of their fictional names. This is identified in table 1 and was used to facilitate the process of data analysis, taking into consideration the socioeconomic situation of each woman and using the 2017 minimum wage in Brazil as a parameter. Group A contains the women with highest family income (over 5 times the minimum wage). In group B are the women with family incomes between 3 and 4 minimum wages, and in group C the women with family incomes of up to 2 minimum wages.

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

Social Actor	Age	Marital States	Children	Education	Profession	Family Income[2]
Ana	35	divorced	2	Technical High School	Attendent	5 or higher
Aline	42	married	1	Post graduated	Dentist	5 or higher
Aurora	56	married	2	Post graduated	Social assistant	5 or higher
Antônia	52	married	3	Technical High School	Housewife	5 or higher
Beatriz	47	married	2	Elementary School	Attendant	3 or 4
Bianca	37	married	2	Undergraduate student	Secretary	3 or 4
Bruna	51	married	3	High School	Sales Worker	3 or 4
Brigite	60	single	-	Elementary School	Babysitter	3 or 4
Carolina	44	civil partnership	-	Elementary School	Production Worker	1 or 2
Cássia	37	civil partnership	2	Technical High School	Housemaide	1 or 2
Cláudia	65	widow	3	First 4 years of the Elementary School	Pensioner - Housewife	1 or 2
Camila	44	divorced	4	First 4 years of the Elementary School	Service Worker	1 or 2
Cristina	38	married	2	High School	Housewife	1 or 2
Carla	55	single	1	Technical High School	Technical Nurse	1 or 2
Clarisse	59	married	3	First 2 years of the Elementary School	Retired – Housemaid	1 or 2

Source: prepared by the author using data from interviews with women participating in the survey in Brazil

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[2] The minimum wage in 2017 was R$ 937.00 (nine hundred and thirty-seven Brazilian Reais). The average family income per capita was R$ 1,271 per month in 2017, and on average 50% of workers in the country earned less than a minimum wage. The data is from the Continuous National Research per Domicile Sample (Pesquisa Nacional por Amostra de Domicílios Contínua — PNAD Contínua), which measured the income of Brazilian families in 2017 and divulged the results by means of the Brazilian Institute of Geography and Statistics (Instituto Brasileiro de Geografia e Estatística — IBGE). (Lencione, 2018)

2.2 Discovering breast cancer

From the moment they feel something is different about their bodies, to when, after appointments and exams, a cancer diagnosis is reached, people go through an entire range of fears and concerns. These arise, for the main part, from the dread of a pre-announced death, due to the stigma of the disease. When the subject is breast cancer, there is the added fear of the changes brought by treatments, such as hair loss and mammary mutilations. (Reis & Gradim, 2018; Melo & Vasconcellos-Silva, 2018).

Breast cancer is a disease which carries a series of implications about body aesthetics, sexuality, and personal and family life. These factors make the disease a present theme in the female universe, emerging in different contexts of social interaction, among which are family groups, work and religious groups, and even those that center on sports and leisure. In addition, the subject is contemplated by the media in a variety of television programs, from soap operas to news stories, and is also present on social media networks and internet sites. (Melo & Vasconcellos-Silva, 2018). The Brazilian public health services add to this commonsense debate by means of a variety of preventive action campaigns associated to early diagnosis, such as for breast self-examination. (Brasil, 2013; Ceolin et al., 2008; Silva et al., 2012).

In this manner, the social actors who fulfil the roles of women[3] seem to live in a constant state of vigilance regarding their breasts, and even each other's bodies. An example of this can be seen in one of the interviews, where a study participant reports how she began to worry about the possibility of cancer: *"(...) there was a neighbor in the countryside who knew I was having these pains, and she said to me: 'that's cancer', and my gynecologist would say: 'no it isn't'; then my neighbor would say: 'yes, it is cancer, just feel it and you will find a thing, a lump.'"* (Clarisse). The excerpt highlights how the concept of alarm is set in motion based on observed changes to the breast, either by the person herself or by those with whom she interacts — in this case, a neighbor.

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[3] The women's social role, in this text, considers the concepts developed by Moraes (2012) that define it as a historical process, marked by changes that began after World War II, which promoted the entry of women to the work force. The author notes: "(...) the stereotype of the submissive woman was replaced, for the most part, by that of the multiple woman: who works away from home, cares for the house, for her children and husband and, even so, must find time to care for herself, improve herself through courses, maintain impeccable hair and nails, practice physical exercise, balance her diet, etc." (Moraes, 2012, p. 260-261)

For 8 (eight) of the women interviewed, the process of discovering the disease began with a suspicion, based on self-identification of some form of breast alteration — either a lump, pain, or some type of secretion — that led to seeking medical assistance. For 4 (four) women, the hypothesis of the disease's existence came up in a routine gynecological appointment that located a node or alteration in the breast tissue during examinations, leading to a mammogram and ultrasounds. Among those interviewed, there were also 3 (three) women who simply acknowledged the possibility of a disease such as cancer due to strong pain in their breasts, and who were directed by family members or friends to seek medical attention. In this last group, one of the participants in the study declared themselves male, which appears to relate to their difficulties with regard to self-exam of the breasts and other practices such as gynecology appointments, that pertain to a woman's routine, as will be discussed at a later moment. For now, we will continue with a description of the process of discovery of the diagnosis.

2.2.1 Establishing a diagnosis

As discussed in 2.1, three groups were created for the study, organized as follows: Group A (highest social tier), made up by participants Ana, Aline, Aurora, and Antônia; Group B (median social tier), with participants Beatriz, Bianca, Bruna, and Brigite; Group C (lowest social tier), composed of participants Carolina, Cássia, Cláudia, Camila, Cristina, Carla, and Clarisse. A line-by-line analysis of the interview transcriptions was carried out, seeking to capture the relevance of certain words or phrases uttered by the women, identifying the instances of context within which these were used and, last of all, the conditions and consequences that led these women to think, act, and express themselves in certain manners, as will be discussed.

Among the participants, the accounts of discovery of the diagnosis point to differences in the processes undergone by the women, and can be grouped into three specific situations: women who identified alterations in their breasts and sought medical help in order to make a diagnosis possible; women who did not notice any changes in their breasts and were only led to a diagnosis after a medical appointment, either with a gynecologist (routine) or another specialist; women who did note changes in their breasts but did not seek immediate help, needing to be prompted by others (people in their lives).

Ana, a participant in group A, carried out self-examinations as recommended by the many Brazilian health campaigns. Like her, other participants were in a similar situation when diagnosis began, including Aline and Antônia, also from group A. In addition to these three, Bianca, Bruna, and Brigite from group B went through the same process, while in group C, Cristina and Carla were the only ones to make the discovery in the same manner. All of these women found something strange in their breasts after self-examination, leading them to seek specialized care. For these 8 (eight) women, suffering began at home, as they became alarmed as soon as they discovered something wrong and remained so until the final moment of the diagnosis process, when the gynecologist handed them a positive result for the cancer biopsy. The words of one of the participants represent the experience these women underwent, in terms of how the diagnosis began for them: *"(...) I was doing the self-exam at home, when I was in the shower. On that day I got a fright, because I found a lump! (...) Then with the exams, ultrasound and mammogram, a tumor was verified, and a biopsy was requested, which confirmed the diagnosis."* (Carla). It is important to note that, among these women, two remained in a state of constant alarm, Bianca and Cristina, as both had a family history of cancer in their mothers and maternal aunts, while the other participants claimed to have no breast cancer history in their families. For all of these, the time frame between discovery of alterations in the breast and confirmation of cancer, after biopsy, varied between 10 and 45 days.

A second type of process took place for Beatriz, who did not note anything different herself; she was at a routine appointment with her gynecologist when she was informed about a nodule. Like Beatriz (group B), participants Aurora (group A) and Cássia (group C) went through a similar experience and mentioned arriving at their appointments without fears and departing in anguish with a series of test request forms. Cláudia discovered the disease when she had a mammogram for an upcoming plastic surgery with aesthetic purposes. In the words of Beatriz: *"I went to a routine appointment with the gynecologist as always, and she noticed I had a lump. I hadn't seen it, I hadn't felt anything! Then she examined it and showed me there was a nodule there."* For these 4 (four) women, distress arrived all at once, after their doctor told them it could be important, and needed investigating. This new-found apprehension regarding the discovery (nodule) remained until their follow-up appointments, biopsy results in hand. Then, the fear of a cancer confirmation, identified in their reports, took over their new exam-filled routines, and extended right up to the final gynecological appointment, from which they were referred to an oncologist — a process that took anything between 20 and 45 days.

Lastly, as a model for a third process of diagnosis awareness among the interviewees, 3 (three) women perceived a nodule or suffered strong breast pains but did not seek out care immediately. These were all women from group C, in other words, the group less favored from a socioeconomic viewpoint. Carolina and Camila only went for a medical checkup when pressured by those in their circle of trust. An example: *"It was after a lot, from everyone insisting, that I went for an ultrasound, and the lady who did the exam said: 'see, that in there is big and ugly, you run and find yourself a doctor, and don't look in SUS, because this is urgent, you look for a private one'*". (Camila) Participant Carolina was an exception, declaring herself male several times during the interview[4], which may reflect upon her difficulty in dealing with practices that are socially constructed for women, such as the self-examinations of breasts, or even gynecological appointments. Carolina suffered pains for around 6 months before seeking out a doctor, only doing so because her partner insisted and accompanied her to the first appointment. In Camila's case, she stated that she did not know that the breast pain she had felt for 4 months, as well as the skin changes that she had noticed, could be a sign of cancer. In her report, she mentions having no knowledge of the subject, and that she tended to avoid appointments due to a fear of doctors: *"At first, I knew nothing of what it was, I had no idea. Then I would tell my work colleagues that I was feeling a lot of pain. After everyone insisted, because I'm terrified of doctors, I decided to go and do some exams."* (Camila)

Finally, also representative of this third process of diagnosis discovery, is Clarisse's case, which differs slightly from the others. She stated more than once during her interview that she had been feeling breast pains for around a year before she had the diagnosis confirmed. Her report points to evidence of medical negligence, as she had sought professional help in her community, after a neighbor alerted her that breast pains could be a sign of cancer. However, in her appointments with the community doctor who attended patients at the local Primary Care Center (Unidade Básica de Saúde — UBS) belonging to SUS, no exams were requested. In her words: "*The doctor out in the countryside knew that I would squeeze, and liquid would come out, but she didn't see a lump. And in 4 appointments she said the same thing: 'you can go because you have nothing, I'm the one who gives a*

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[4] Carolina, who several times declared herself male, also stated never having been to the gynecologist before getting sick, as this is, *"(...) a woman's thing and I am and always have been a man".* However, on being questioned about the pronouns used to refer to herself — sometimes 'he/him' and other times 'she/her'— she confirmed the preferred use of female pronouns, justifying this choice as a sign of respect for her mother, who was still living at the time. According to Butler, as cited by Saflate (2015), the concept of gender is linked to the theory that seeks to understand the manner by which subjects deal with norms — which in turn stem from the senses constructed for sexual differences — by subverting these norms to find spaces of singularity and produce new forms of dialogue. Thus, Carolina acts as male, but prefers female pronouns, and this study respects her choice.

cancer diagnosis, not your neighbor.'". (Clarisse) The situation was only resolved when she contacted her daughter, telling her she had been to 4 appointments with the same doctor, who had taken no steps. The daughter, who lived in the state capital, drove to the countryside to fetch her mother and brought her to a private mastologist, who confirmed, based on exams, intermediate stage cancer in both of Clarisse's breasts, requiring extensive surgery.

From this process of diagnosis confirmation, we can extract that different points of view regarding a phenomenon create different attitudes toward it, some more favorable than others. Also, that social positions and networks can favor some social actors over others. According to Adam and Herzlich (2001), the analysis of phenomena relating to positioning during the discovery of diseases should include the investigation of the different social groups, that produce visions, strategies, and values directed at health care services. Within these groups, the social actors deal with concepts that they select and assimilate with basis on their cycles of family, educational, and, later, work interactions. These concepts are applied by social actors in their day-to-day and include those connected to physical and psychological symptoms, leading them to hypothesize the possibility of having a disease. Therefore, social surroundings produce directly or indirectly the different health forms and conditions, as well as the access to health care services, and these are always connected to the socioeconomic and individual variables of social actors.

The matter of the existing relationships between lifestyle and health can be analyzed as the product of a set of broader structural relationships in society. Unfortunately, in the case of serious diseases such as cancer, a long wait with already-present symptoms such as nodules and/or pain can mean diminishing chances for a cure.

2.2.2 Sharing the news and identifying a support network

An important stage for the study participants was sharing their diagnosis. To tell, not to tell, or even deciding who to share the cancer diagnosis with — all of this posed a certain dilemma for the women. In most of the reports, they decided the time and people to inform about what had happened. For the most part, the first person chosen to share the diagnosis with was their life partner, considering the 11 (eleven) women in the study who declared having one, 10 (ten) of which were married and one divorced (but with a fiancé). Only 4 (four) of the women had no romantic partner, 2 (two) being single, one a widower, and the other divorced. In the case of these last, the first people to be informed of the disease had different social roles in their lives.

In group A, all the women were in domestic partnerships, 3 (three) with husbands and one with a fiancé she was soon to marry. In this group, without exception, the first people informed of the cancer diagnosis were the domestic partners. These men were immediately told after the doctor's confirmation, with 3 (three) of the partners already at hand in the waiting room. This points to the trust these women had in the people they shared their intimate life with, and the support they sought in these partners. Only Aurora, in this group, felt her husband did not support her in this situation, becoming, in her perception, more aggressive and aloof after confirmation of the disease.

Bruna and Bianca (group B) had similar experiences of acceptance and caring with their partners, who were also the first to be informed of the disease. Beatriz was another whose husband became, according to her, strange and more aggressive after hearing of the diagnosis, coinciding with the attitude of Aurora's husband. In group B, only Brigite identified as completely single, and confided the diagnosis first to her niece.

Cássia, Cristina, and Clarisse, from group C, also informed their domestic partners first of the cancer diagnosis. These women felt well-accepted when they shared the news. Carolina, who lived with her wife, reported that her partner not only dealt with the news with acceptance, but was the person who most encouraged Carolina to seek treatment, according to the participant.

Group C also included Cláudia, Camila, and Carla, women without romantic partners at the time of the study. Cláudia, a widower, first told a sister of the diagnosis, and later her children and adult grandchildren. Camila, a divorced woman, first shared the news with her children. Last of all, Carla, who was single at the time, first told her work colleagues of her diagnosis — all health care professionals, like herself — to later tell her adult daughter.

To summarize, most of the women identified their domestic partners as the first people to whom they could entrust their diagnoses, seeking in them, at the same time, the initial support they needed to deal with the disease. However, it is important to point out that 2 (two) of these women, one from group A and the other from group B, could not count on these men as part of their support network. As mentioned previously, their husbands were not supportive after hearing of the disease, as can be seen in Aurora's report: *"He drinks a lot, and now, after the diagnosis, he's drinking even more. Today, for example, is a Friday... He drinks a normal amount from Monday to Thursday, but when it comes to Friday he goes from Friday to Saturday and Sunday, drinking non-stop. He's a lot more work."* (Aurora)

Sharing the news, for participants of the study, was something that emerged not only as a manner of alleviating the distress they were feeling, but as a first step toward building a support network in the fight against the disease. In the following reports, this is made clear by several of the women, who said they could count on their husbands before diagnosis, during confirmation, and, finally, at the moment they had to start treatments: 1) *"So I myself felt a nodule and I even showed my husband, who went with me to the exam. (...) It was on the day of the ultrasound that I told my mother and my father that there was something wrong, and that I would need a biopsy."* (Cristina) 2) *"I immediately shared it. I got the results and talked to all my family, but first I told my husband, who was there with me. And, poor thing, he was devastated!".* (Bianca) 3) *"Also, my husband didn't let anyone go to chemotherapy with me, he went with me every Monday. He took this day off for me, so every Monday I can count on him to take me to the treatments, to do exams, and everything else."* (Antônia)

Adult children appeared next, after spouses, as important pillars of support and trust for the women in the study. For one woman, a widower, this role was undertaken by her grandson, an adult who lived with her as if he were her son. These family members accompanied them to exams, chemotherapy, and other treatments. They also acted in a more solicitous manner at home, sharing domestic chores with the sick women. Even those who no longer lived at home, because they were married or they worked/studied away, came back frequently to help their mothers. Many also contributed financially, helping out with treatments. Thus, the disease appears to have acted as an incentive toward the reorganization of family roles and functions. According to one participant: *"The oldest* (referring to one of her children), *even began helping me financially, showing that he has a responsibility to me. I could see clearly the love of all my family, then, I could see all of that, especially the love of my children."* (Camila)

In third place, in terms of support, were the women's sisters, identified by most as extremely worried, both by the situation and by the risk of being diagnosed with the disease themselves. According to most of the reports, the women's sisters helped in different way, such as with meals, bathing support, or assisting with bandages after surgery. Only one woman, Beatriz, complained that, despite having 3 sisters, all of whom lived close, none of them helped out; in fact, they distanced themselves, claiming it was, in their words: *"(...) for fear of cancer".*

There was one more exception among the reports that mentioned the role of sisters in support networks — the case of one who, in the words of the participant, *"started to panic"* (Bianca) about the participant's illness. According to the participant, they had already lost a maternal aunt to breast cancer, and their mother was being treated for the disease at the same time as Bianca. When her sister realized the issues Bianca was dealing with, she distanced herself from all her family and had a radical mastectomy in both breasts. Bianca's sister only reestablished ties later, bringing life-decision questions for her supposedly dying sibling. According to the participant, at that moment she realized the psychological dilemma that had previously pushed her sister away: *"She came to visit me, crying and saying: 'I'll take care of your boys, don't worry, I'll care for your children!' I told her: 'What do you mean? I'm not going to die, there's a cure and I'm fighting to be cured. I'm going to take care of my children!'"* (Bianca) This situation exemplifies the overwhelming fear that cancer represents for some people, who deal with it as if it were a death sentence. Bianca added that initially she was angry at her sister, but soon realized she had been suffering during the entire situation: *"I was furious when she talked about taking in my children, but soon I saw that she was really a little freaked out, and she didn't know if it was because she was afraid I would die from cancer or if it was that she might also have the disease."* (Bianca)

In fourth place, in terms of support network, the women in this study could count on their friends, especially those in the immediate circle. In two specific cases, where the participants had no biological sisters, their close friends took on similar roles. Some of the women from the three groups in the study also included their neighbors among those important to their personal support networks.

This topic also includes the theme of non-disclosure, or a late disclosure of the diagnosis. Some women kept the information from certain people, such as elderly or ill parents, young or adolescent children, work colleagues, and specific family members. This positioning took on two distinct forms within the studied groups. A first one consisted in hiding the disease in an attempt to protect loved ones from suffering, something the women believed would happen if news of the disease came at an inopportune moment. The following is an example: *"(...) I didn't share it immediately even with my mother, because apart from her being old, she was sick at the time. I only told her when she was better."* (Carolina) 3 (three) other woman — one from each group — acted in a similar manner. A second path associated to non-disclosure the diagnosis was linked to self-preservation, avoiding social exposure or judgement, especially the belief that the sick person must be close to death. This occurred with three women in the study, from group B and group C. The example in the following quote exemplifies this behavior:

> But really what hurts me are the people who come up and say: 'this person had cancer and died' or 'that person has the disease and is really sick.' That's bad for anyone. If I say that I'm sick, they'll say that I'm dying! So, what do I do? I don't tell them I'm sick, even if some of them notice because of my lack of hair or of how much weight I've lost. I just keep quiet. (Bruna)

It is worth noting that 3 (three) women in the study, all from group A, spoke in a more elaborate manner about how they went through this process of subjectivation[5] while they were sick. Based on this, it is understood that they made an effort toward self-awareness as well as an appropriation of what they would be living through as they dealt with cancer. This led to these women choosing what to tell, to whom, and when to share news of the diagnosis. Their reports suggest their ideas and feelings were discussed in psychological therapy sessions, as all three said they were receiving help from psychology professionals while they became sick and had been through psychotherapy at other moments of their lives. The segment below summarizes the way one interviewee sought to organize herself after she received the diagnosis:

> Because when you receive this news you have to choose the path you want to follow, because you have the path of fight, you also have the path of feeling self-pity. Anyway, you have several choices and I had to see which one I would hold onto. I had to know which one would resonate, and how that would be for me! So I chose like this, I first wanted to know everything, properly, and after that I shared with my kids, with my mother, and other people in my life. (Ana)

In Ana's report, she appears to try to comprehend her own subjectivity, deciding how she would behave after the diagnosis was confirmed. For her, women could choose between a "*path of fight*" or the "*path of feeling self-pity*". Like Ana, participants Aline and Antônia spoke of their efforts to deal with the feelings and behaviors that emerged immediately after they confirmed they had the disease, and how this influenced their family relationships. Both affirmed their psychologists helped greatly during this process of "*acceptance of the disease*". According to Aline: *"I was even thinking of leaving therapy, because I'd been there for ten years. But it was her support (*psychologist*) that helped me accept the disease and gave me strength to face this in my life."*

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[5] The process of Subjectivation, according to Parpinelle and Fernandes (2011), goes beyond the duality involving subject and object, "(...) Instead of considering a subject closed within its interiority, based on which subjectivity is formed, it would be better to comprehend subjectivity as the intersection of countless components of subjectivation that connect and reconnect intermittently, converging and endorsing the process of subjectivation of subjects." (Parpinelle & Fernandes, 2011, p. 198) For the authors, the subjectivation processes occur in the infinite interactions of the subject within their social sphere, and this is the concept adopted in the present text.

2.3 Dealing with treatment

Several authors have contributed to the biomedical literature on breast cancer, discussing the different types of treatments available and in current use in the fight against the disease. The literature also addresses important epidemiological data, as well as the relevance of screening for an early diagnosis. In addition, many authors discuss the collateral effects of the treatments for the disease, suggesting conducts to mitigate these. (Ashing-Giwa et al., 2004; Porter et al. 2009; Youlden et al., 2012, Bray et al., 2012; Maluf, Buzaid & Varela, 2014; Panobianco et al., 2014; RKI, 2015; Fayer, Guerra & Cintra, 2016; Kozir, 2018). The present study helped in better comprehending the phenomenon of submitting to these treatments, since the women shared in the interviews, often in great detail, the challenges they faced daily during the treatment process.

The surgical procedures that the women in the study underwent were some painful types of biopsy, surgeries either for partial or radical mastectomies, and, in some cases, axillary dissection. Another treatment — the most mentioned subject — was chemotherapy, which the women named the “*red, the terrible*” and the “*white, the light one*”. Radiotherapy was also a theme brought up in the interviews but was less prevalent as a subject than chemotherapy. And finally, the commercial name of a medication was often mentioned by the participants — Herceptin, a type of hormone therapy. According to them, this medication was prescribed as a preventive against cancer recurrence in specific cases. According to the Brazilian Society of Mastology (Sociedade Brasileira de Mastolgia, 2017), Trastuzumab, registered in Brazil under the commercial name Herceptin®, is a 95% humanized antibody, made from biological cells, that works on the receptor known as Her2, a form of protein that is abundant in the tumoral cells of specific types of cancer. When the antibody connects to the protein, it causes functional disturbances in the tumor cells, leading to their deaths. It does not attack other cells — the organism’s healthy cells — and is considered for this reason to be a less aggressive form of treatment. In the present decade, the medication has been often prescribed for Brazilian women with the breast cancer subtype “Her2 positive”.

Table 2 summarizes the history of disease and treatments for the Brazilian women. The table also marks what form of health care these women were using to ensure treatment. Six out of the fifteen participants were being treated through the Brazilian public health care network, SUS, without any direct costs. Of these, 5 (five) women were in group C (of the previously mentioned socioeconomic classification) and only one was from group B. Three of the women were being treated through health care services offered to employees of the State of Minas Gerais (IPSEMG), with 2 (two) of these belonging to group A and one to group B. Additionally, 6 (six) women were being treated by means of private health care services, also known in Brazil as Supplementary Health. Out of these women, 2 (two) were in group A, 2 (two) in group B, and the last 2 (two) were from group C. Access to public health services is a right guaranteed to all citizens by the Constitution, as discussed in the Introduction. However, due to resource issues affecting the agility of services, many people, even those living in poverty, have migrated to private health care.

The women interviewed underwent different surgeries that, based on the guidance of medical texts, are considered definitive treatments for breast cancer. Surgery for breast cancer should relate directly to the size and location of the tumor, as well as infiltration or not of lymph nodes. It is interesting to note that the women appeared to be very well informed about the different types of surgery they received as well as the reasons for this therapeutic decision. 3 (three) women in the study, Camila, Bianca, and Brigite, went through radical mastectomies, which completely removes the breast, including the areola and nipple. Of these, only Bianca had breast reconstruction, resorting to private health services. 3 (three) other women, Ana, Cristina, and Carolina, had also been flagged for radical mastectomies, and at the time of the interview were awaiting surgery, scheduled for the near future. Of the remaining women interviewed, some underwent surgery considered as partial, known in the medical world as segmental mastectomy or quadrantectomy. 7 (seven) of the participants went through this type of procedure: Aline, Beatriz, Cássia, Cláudia, Aurora, Clarisse, and Bruna. This form of surgery removes a quadrant of the diseased breast, extending beyond the contaminated nodule or tissue, but is preservative in nature, aiming not to mutilate the woman.

Table 2 – Diagnosis and Treatment of Brazilian Women

Social Actor	Health Coverage	Cancer type	Diagnostic Time in months	Treatment Surgical	Chemotheray treatment	Treatment Radiotherapy and Medicines
Ana	IPSEMG	Lobular Carcinoma Invader with axillary contamination	7	Future right radical mastectomy	20 sessions	Herceptin®
Aline	IPSEMG	Invasive Papillary Carcinoma	7	Right quadrantectomy	20 sessions	In progress, 8 sessions
Aurora	UNIMED	Mammary Carcinoma Not Specified	7	Quadrantectomy with axillary dissection left	In progress 4 sessions of 16 prescribed	-
Antônia	UNIMED	Invasive Ductal Carcinoma Metastasis*	9	No information on surgery - right breast	20 sessions	Herceptin®
Beatriz	Saúde Sistema	Invasive Ductal Carcinoma	8	Quadrantectomy with axillary dissection left	12 sessions	- Tamoxifen +Antidepressant + Anxiolytic
Bianca	IPSEMG	Lobular Carcinoma Invader Lymph Node Metastase	24	Left radical mastectomy with reconstruction	20 sessions	- Herceptin® +Antidepressant + Anxiolytic
Bruna	UNIMED	Invasive Ductal Carcinoma Metastasis *	9	Quadrantectomy of the right breast with sentinel lymph node research	In progress, 7 sessions of the second stage of 20 sessions	- Herceptin® +Antidepressant + Anxiolytic
Brigite	SUS	Invasive Ductal Carcinoma Metastasis *	5	Left radical mastectomy plus axillary dissection – without reconstruction	In progress, 2 sessions of the 16 prescribed	- Herceptin®
Carolina	SUS	Lobular Carcinoma Invader Metastasis*	5	Future right and left radical mastectomy (under analysis)	In progress 4 sessions of 16 prescribed	-

Social Actor	**Health Coverage**	**Cancer Type**	**Diagnosic Time in months**	**Treatment Surgical**	**Chemotheray treatment**	**Treatment Radiotherapy and Medicines**
Cássia	VIVA-MED	Lobular Carcinoma Invader	11	Right quadrantectomy	7 sessions	- Herceptin®
Cláudia	UNIMED	Infiltrating Ductal Carcinoma	8	Right quadrantectomy	2 sessions (of 16 prescribed and interrupted)	15 sessions
Camila	SUS	Inflammatory Ductal Carcinoma Lymph Node Metastases	7	Right radical mastectomy - axillary emptying - Without reconstruction	9 sessions (of 16 prescribed) - pause for new exams	-
Cristina	SUS	Inflammatory Ductal Carcinoma Lymph Node Metastases	7	Future right radical mastectomy - with axillary emptying	In progress 10 sessions (of 16 prescribed)	-
Carla	SUS	Lobular Carcinoma Invader Lymph Node Metastases	6	No information on surgery – left breast	In progress 15 sessions of 16 prescribed	- Antidepressant + Anxiolytic
Clarisse	SUS	Lobular Carcinoma Invader Pulmonary metastases	12	Bilateral quadrantectomy with emptying of both armpits	In progress 4 sessions of the second stage of 12 sessions	- Antidepressant + Anxiolytic
* Metastasis whose location was not yet well understood by the tests already performed.						

Source: prepared by the author using data from medical records and interviews with women participating in the research in Brazil

It is worth noting Clarisse’s history, as she took a long time to receive a diagnosis and had to have bilateral surgery, as the cancer was in both breasts. Of all the study participants, only Antônia and Carla had not yet been prescribed surgery as a treatment option.

One situation stood out for the researcher: one of the women, who depended entirely on SUS, underwent radical mastectomy to remove a breast that weighed 1.780 kg. The fact that she had no breast reconstruction or even removal of the other breast (also large, according to her) created an imbalance in body weight that was causing her back trouble. During the interview, which occurred at her place of residence, it was visible that she moved unequally, and also possible to hear her low moans of discomfort, upon sitting or rising — situations that left her feeling highly embarrassed. According to her, she was in a lot of pain and had already complained to the surgeon and the oncologist, but she did not feel that she was being heard. In her words:

> After two months of surgery I returned to the doctor and said: ‘Oh doctor, I’m carrying a pregnancy of nearly six months hanging off the left side of my body, on my thorax, with 1 kilo and 780 grams. Because my breasts were the same, right?! You took one and left the other. What do we do with that? My back is aching too much! You’re not going to leave this *(referring to the healthy breast)* hanging here, are you? You have to take this one off, too!’. (Camila)

As discussed in the introduction, chemotherapy, radiotherapy, and even hormone therapy are used as treatments. If employed before breast cancer surgery with the aim of diminishing the tumor and leading to a less extensive surgery, they are known as neoadjuvant therapies. In cases where they are applied after surgery, they are called adjuvant therapies, and are normally used to prevent recurrence or to destroy possible sources of tumor in other locations. According to Maluf, Buzaid, and Varela (2014) and INCA (2019), in certain circumstances, when doctors identify that the benefits outweigh the risks, these treatments are used both before and after surgery.

Chemotherapy deserves special attention, as this is the procedure that all participants had been through, or in 7 (seven) cases, were still undergoing. Besides, as previously mentioned, this was a subject spontaneously brought up in the interviews as a great challenge for the women. Radiotherapy had only been prescribed for 2 (two) women, as the remaining had no recommendations for this procedure. As for hormone therapy, only one of the Brazilian women received Tamoxifen, while 6 (six) women were specifically prescribed treatment with Herceptin® (Trastuzumab) and were still receiving this medication.

2.3.1 Winning the Chemotherapy Tsunami

The subject of chemotherapy deserves an exclusive subchapter, since the word chemotherapy, or just chemo, was repeated many times in all interviews, accompanied by expressions of upset and discomfort. But why a tsunami? One of the women interviewed associated the experience of chemotherapy with being overcome by a tsunami: “*Chemotherapy was a tsunami for me.”* (Carla) She goes on to say: *“tsunami are devastating waves that arrive from the sea without anyone expecting them, invading beaches and cities, bringing all kinds of destruction in an unexpected way. So, chemotherapy was a tsunami for me.”* (Carla) For this woman, as for all the other participants in the study, chemotherapy brought many changes for the organism, from the physical to the psychological and/or emotional. According to the reports of their experiences, this type of treatment stood out as invasive and devastating, manifesting throughout their illness as an intrusive component [6] in these women's lives.

After reviewing the reports on chemotherapy, it was possible to pinpoint the difficulties experienced by the women in dealing with the many collateral effects that emerged in their bodies and emotions. All of them affirmed they had been informed previously, and therefore knew to expect hair loss; some also knew they would lose their eyelashes, eyebrows, and pubic hair. However, this did not preclude them being upset by all of these occurrences.

Among the most difficult experiences, causing consternation and even "*panic*" — a word found in the reports of Aline, Beatriz, Bianca, Bruna, Carolina, Carla, and Clarisse —, were: nausea, mood swings (irritated or depressed), a paralyzing exhaustion accompanied by insomnia (or difficulties in sleeping), loss or transformation of nails (most women's nails became dark and weakened), loss of sense of taste, dry mucus membranes, and, finally, some women reported losing previously healthy teeth, or suffering skin lesions, especial on their buttocks or face. Additionally, their diet had to be radically altered, as food that had previously been a part of their lives now caused diarrhea and consequent dehydration. Looking at these aspects, experienced on a physical and/or psychological level at a higher or lower intensity by all of these women, it is possible to understand the sensation of devastation, named by one of them a "*tsunami".*

All women in group A reported reading, researching, or calling doctors and nurses (using the emergency numbers for people undergoing chemotherapy) when they felt they were, according to some, in the *"eye of the hurricane"*; in other words, very ill from some of the side effects and with no control over the situation. This means that when they were experiencing a symptom that they could not manage on their own, or by using the prescriptions at hand, they would seek help. This positioning indicates not only their education levels and ability to seek assimilation, but mainly their efforts to take control over the moment. This can be seen in this excerpt from Aline's interview:

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[6] Charmaz (1997) considers as a chronic and intrusive disease that which demands continuous attention, prolonging itself in the life of the ill person in terms of treatment time and forcing them to adapt. The author also mentions that the sick person makes every effort, some successful and others not, to minimize the disease's intrusion in their lives. Treatments, according to the author, often bring the same components of intrusion to the sick person's life, as they cross over into all usual activities, with permanent symptoms that diminish the physical and psychological potential of the sick person. Therefore, the suffering that stems from this experience with intrusive symptoms cannot simply be forgotten/neglected by the sick person.

> In the first chemotherapy session I felt very ill, but really ill. But Cetus has a program where you can call and get your questions answered. So I thought, I'm not going to sit here feeling sick, so I called, and it was so simple! The nurse just asked me to change the nausea medication, I can't remember the name of the one I was taking, but she told me to change it to Plasil, and that really worked. (Aline)

It is worth noting that the women in group A also had a stronger personal support network in terms of financial assets and education levels, with family members who worked in health care professions. Thus, they had more resources than the others when seeking professional help or precise information. Their reports mention relatives who were doctors (two brothers of two of the women), psychologists (including one husband), nurses (siblings, cousins, friends), or other professionals, all cited as people who helped in some aspect during the treatment process. In the other two groups, only one woman, Carla, who worked as a nurse technician, had a support network similar to that of group A. Carla's work colleagues, including doctors and nurses, helped to manage the side-effects of treatment in a variety of ways.

All the women in group B, and the remaining participants in C, distinctly stated they felt lost and alone when experiencing strong chemotherapy side effects. This was also noted when they had questions about their treatment that they did not feel had been sufficiently answered by health professionals. Their reports make it clear that, despite the affection and attention they received from family members and friends, this was not sufficient for the support they required in their moments of despair, when they needed to learn how to control the situation. Two different reports follow, both from women in group C: "*I was very shocked, I was really upset. I was scared, terrified and afraid, because I was feeling a lot of bad things. My daughter kept saying it would pass. But you feel like you're going to die, that death is on its way!"* (Clarisse). Clarisse named 'imminent death' the things she felt, physically and emotionally, after the first chemotherapy sessions. The fact that her daughter tried to calm her, affirming that the sensations would pass, did not bring relief, as she continued to be fearful.

The next extract, from participant Carolina, reveals different important aspects of the phenomenon:

> The sensation is that chemotherapy brings all sorts of junk into your body. I don't know... You don't feel well! You go crazy, crazy, crazy, crazy, but then you have to try and control yourself. You fight with your mother, with your partner, with your son and even your cat. Because it's really very difficult. You feel strange. They have to find another way to do this treatment, because like this, the way it affects you, honestly...! If the person doesn't know how

> to control themselves, this thing *(chemotherapy)*, this can kill. You die, but really die! (Carolina)

Carolina states that the suffering related to chemotherapy took from her any sense of self-control. She felt estranged from herself and associated this to the side effects of chemotherapy. She even mentions she felt herself going crazy from the treatment, placing upon chemotherapy the blame for the fights taking place in her home. It is interesting to note the tone of voice with which she narrated the facts, predominantly brusque and aggressive. She was clearly upset with everything that was happening and, in some way, appeared to find that the interview provided a moment of freedom to express her anger and sadness regarding the treatments. Carolina was completely desolate, physically and emotionally drained by the experience of dealing with chemotherapy; also, she felt confused by not recognizing herself during the process.

In the studied cases, it was clear that 10 (ten) women among the 15 (fifteen) participants suffered notably more with chemotherapy than the others, either due to continued exposure to side effects, which they did not know how to control, or due to a lack of access to resources that could help alleviate the symptoms. On the other hand, the remaining 5 (five), despite also suffering, did not report this as a devastating experience, but as a moment of challenge and of seeking resolution for the problems caused by treatment side effects. In this study, it was evident that the loss of a sense of control over the circumstances also led to a higher level of suffering.

The question that emerged for the researcher when hearing and, later, analyzing the reports, was: how could they all continue their chemotherapy treatment, or even complete it, while going through so much adversity? To summarize, how did they beat the chemotherapy *tsunami*? They all wanted to survive, to overcome the disease, and this epitomizes their persistence in submitting to treatment. However, to understand the phenomenon in depth, some points were clarified, culminating in interconnected findings for these women with regard to their adaptation to the treatments and the changes in their identity goals.

According to Charmaz (1995) it is important to identify that the sick person goes through what the author called adaptation:

> To explain how body, identity, and self intersect in illness, I describe a lifestyle that takes into account a compromised or loss of bodily function during adaptation. By adaptation, I mean altering life and the self to accommodate physical losses and reunite body and self accordingly. Adaptation implies that the individual recognizes this incapacity and alters life and self in a way that is socially and personally acceptable. Corporeal limits and social

> circumstances generally force adaptation to loss. Adaptation sets the tone for acceptance. Thus, sick people adapt when they attempt to adjust and flow with the experience of the disease. (Charmaz, 1995, p. 657)

This adaptation, states Charmaz (1995), consists of three main stages for those who deal with chronic illness: 1) experiencing an altered body, defining damages and losses; 2) evaluating this altered body, the appearance of self and of others, and the context of present-day life, resulting for the most part in reducing identity goals due to physical losses and restrictions; 3) surrendering to this sick body, opening up to the experience of unifying body and self, within these conditions.

To understand identity, Charmaz (1995) adopts a symbolic interactionist perspective, citing Hewitt – 1992; and describing personal identity as the manner by which an individual defines, locates, and differentiates the self from others. She also mentions Mead, one of the precursors of social psychology, as an anchoring point in comprehending and defining identity. Thus, in the aforementioned text, she avails herself of the author to better clarify the subject. Mead (1984) suggests that social psychology should consider the formation of the self as directly related to intersubjectivity and symbolic communication, structured by a subjective matrix. The author completes this explanation by arguing that individuals, by taking on social roles in the different relationships they establish with others, internalize the structures of the self. Within this perspective, the subject differentiates themselves from others they interact with, within a process of self-comprehension that simultaneously recognizes what they carry within and what belongs to others, as well as that which they bring and that differentiates them from this immediate other. (Mead, 1992)

To explain identity goals, Charmaz explains that human beings create meaning and therefore act intentionally when interpreting their experiences and interacting in the world. Identity goals emerge from these intentions, life objectives, desires, and behaviors, which for some people are implicit, undeclared, or misunderstood. However, others may have explicit preferred identities that they understand very well. In short, for the author, identity goals are the preferred identities of an individual, at a given moment and circumstance. (Charmaz - 1987 *apud* Charmaz, 1995).

It is also important to note how the author considers the idea of the identity hierarchy that is established in a sick person’s life throughout time, especially for those with a chronic and progressive disease:

> A hierarchy of identity becomes evident as, with the passing of time, ill people choose distinct types of preferential identities, reflecting a relative difficulty in achieving specific aspirations and objectives. The types of preferential identities constitute certain levels of identity in a hierarchy of identity. These levels of identity include: (1) an above average social identity, an identity that demands extraordinary achievements in conventional life spheres; (2) reestablished identity, a reconstruction of previous identities, from before the disease; (3) contingent personal identity, an identity that is hypothetically possible, although uncertain, because of a new disease; and (4) protected identity, the conservation of an identity of the past, based on an activity or a valued attribute, when becoming physically dependent. (Charmaz - 1987 apud Charmaz, 2009, p. 170).

In the present study, some identity goals could be found, linked to the adaptation of the women while undergoing treatment, and more specifically the consternation produced by chemotherapy. Thus, some women went through adaptation by surviving the day-to-day of treatments supported by a **protected identity goal**, or in other words, by the idea of preserving their self-concept, believing that as soon as it was all over, they would return to their previous state, or their former self.

> I did this treatment (chemotherapy) so I could get better, because I have a lot to do, I'm very active and I can't stay in a bed. I like to walk, to move, I like to use my head, I'm very intelligent... And I just didn't have any education, see?" (Carolina)

As can be noted in Carolina's words, she was dealing with her treatments by aiming at recovering her activities, considering herself an active and intelligent person and stating, *"I like to use my head"*. In a similar manner, although in ways that are implicit to each, another 5 (five) women, Bruna, Brigite, Carla, Cláudia, and Cristina, appeared to adopt a protected identity goal during treatment. They had fixated on physical and psychological characteristics or abilities that set them apart before the disease and were pursuing the aim of reestablishing them by supporting treatments.

Another form of adaptation was managing each moment of treatment by means of a **contingent personal identity**, either acting as a strong and determined person, or as fragile and completely subdued by adversity or extraneous interests. Five of the women took this positioning, implicitly or explicitly: Aurora, Beatriz, Cássia, Camila, and Clarisse. It is interesting to note that three among them began taking antidepressants and anxiolytic medication after they discovered they had the disease. One of these began mixing alcohol with her medication after she suspected cancer and had not yet stopped this practice. They alleged that psychopharmacological medications were a source of support against sleepless nights, and to keep them from giving into the tears and sadness they were feeling. Camila's example can shed light on how she was experimenting with contingent identity at the time:

"You see so many young women who die, who lose their lives early, because I've heard cases of women who died because they didn't want to do the treatment. In my case, I do the treatments (chemotherapy) *because I think about my children."* (Camila) When she compares herself to women who die young due to lack of treatment, she states she is getting treated, because she identifies as a mother and wants to be healthy for her children. Her health, according to her report, is contingent to her maternal role. For this group of women, God and/or their children were mentioned as reasons to live or survive. It was not possible to identify, within their statements, survival goals based on their dreams or about simply enjoying their existence.

This adaptation brought to some women a sense of being a model for struggle and resilience as they faced the disease, demonstrating to themselves and to others that they were exceptional people, capable of overcoming adversity and also helping others. This posture is associated to an **above average social identity goal**. Acting in this manner, and explicit regarding their preferred identity at the time, were 3 (three) women in group A and one in group B: Ana, Antônia, Aline, and Bianca. The following excerpt follows one woman's experience, who states she did not agree with the *"drama role"* of women undergoing breast cancer treatment. This segment also represents the other women who felt similarly:

> One day I saw this woman's arm all purple, so I asked her what was that?! She said that the nurse got her vein wrong five times. So I said: 'but you let her get it wrong five times? Because on the second time she got it wrong for me, she wouldn't put her hands on me again.' So it's like this, I get worried if women have this passivity to actually suffer, or to get into a drama role. Because there's a lot of passivity, but I don't agree with it. (Aline)

Aline did not deny suffering with the process, from diagnosis to chemotherapy and, finally, radiotherapy. What is different about her is that she refused to suffer passively. Thus, in distinct moments, she revealed that she had used arguments to clarify doubts and to solve her difficulties, as well as to support her colleagues who were in the same treatment sessions.

Overall, significant processes of personal suffering were identified among the women in the study, either physical and/or psychological, and were for the main part associated, according to the women, to side effects of the treatments. The key difference was in how this suffering was managed, and how they adapted to it. At the time of the study, the women were not entirely finished with their treatment, however, none had experienced **reestablished identity goals**. However, as will be explained in detail in item 2.6, there was a verifiable connection between the identity goals recognized during the process of fighting the disease. Some brought gains — and in consequence, an apparent reduction in suffering; others brought losses — and consequently an apparent succumbing to suffering. In sum, the women who took on an above average social identity goal seemed to deal better with themselves, in terms of managing pain and adversity, and also in managing interpersonal relationships, either at home or in other contexts.

The women who experienced a protected identity were divided in subgroups: for some, the disease was destroying their existence, since they experienced suffering as something devastating; for others, who could already imagine improvements and had some perspective of the future, suffering was faced as something manageable or transposable. Finally, the women with contingent identities were also subdivided. For some, suffering was helped by faith or by their children, and they found in atonement or in their goals of raising their children the answers they needed to handle pain and loss. Others seemed to have no expectations of a future for themselves, and were overcome by pain, by loss, and by a lack of hope.

2.4 Self-management during sickness

If, at a first moment, it was necessary to absorb the discovery of cancer and, immediately after, submit to the treatment process, next came the need to manage the new corporeal experiences, which often brought sickness and discomfort, as mentioned previously. During these stages, most of the women were concerned with maintaining their distinct social roles — mother, wife, and in some cases, professional. To continue to be socially inserted, they fought to adjust their different subjective experiences to their new physical experiences.

What exactly is cancer? This was the question asked by the researcher upon finding this excerpt in one of the interviews: *"So it* (cancer) *is not just a disease, because treating it is not just about taking the medicine, or doing chemotherapy, surgery, radiotherapy, you know, it's an issue that really affects human beings, that brings a radical change of life."* This came from Ana, expressing the concept she had constructed regarding cancer and its implications in her life, and it stood out for the researcher for the use of the expression: "*radical change of life".*

With basis on this concept of "*radical change of life*", the testimony of the other women was examined for mentions of their lives before and during cancer, since they were still undergoing treatment. Their statements highlighted situations of intense change, all associated to the process, such as a pregnancy in one woman's life, the beginning of divorce procedures for 2 (two) others and, finally, the struggle to find themselves in their new daily routines. All of their lives, during treatment, demanded a rigid dietary discipline, a new control over physical activities, self-care as different parts of the body became sensitized, and also a daily dedication to finding clothes and accessories, so they could continue their routines. The next section will examine specific situations that were identified in the study, and that deserve attention for the changes caused by the disease not just in the lives of the women, but in the arrangement of their family groups.

2.4.1 An unexpected pregnancy

One of the participants became pregnant during her treatment, and she reported that this situation brought anguish and moral questioning. For the researcher, the experience of listening to the account helped broaden her perception of the power and influence of medical discourse on the lives of a segment of the population. The situation was narrated in detail by the woman, identified as Cássia, during the recorded interview, and then in further depth after the recording device was turned off. However, it will be summarized for a general understanding of the facts: Cássia said that after receiving a confirmation of cancer, she was told to immediately suspend use of her birth control medication. The doctor alerted her to the risks of this medication making her case worse and prohibited her from continuing on this form of birth control. Although Cássia told the doctor she didn’t want any children, and that her husband refused to use condoms, she was not given any other recommendations for contraceptive methods. Opting to follow medical orders, she suspended her oral contraceptive and began individual attempts to avoid pregnancy. However, her efforts were not successful, and she became pregnant. In her words:

> When the result came out, the mastologist gave me the cancer diagnosis and told me to stop my birth control immediately, because it can feed the cancer, it didn’t cause the cancer, but according to her it was feeding the cancer. But she also told me I absolutely could not get pregnant. But because I was careless, I got pregnant! When I got the pregnancy exam in August, I got a great fright because I never imagined I was pregnant, and my cancer surgery was set for October. (Cássia)

In this excerpt, it is possible to identify that Cássia felt guilty for becoming pregnant after receiving her diagnosis. Not just guilty, but frightened. However, a medical professional gave her the order to suspend birth control, without offering another option. But her report does not place responsibility with either the doctor or her husband. Subjectively, she is taking all responsibility for the facts, and adding it to her sadness and insecurity.

Thus, a baby emerges on the scene, in midst of the treatment process; a child that the woman and her husband did not plan for. Caught up in the fight to survive the disease, Cássia had to go through other complex experiences, such as the fear of suspending treatment in order not to harm the baby, and at the same time risk the disease advancing; or choose to undergo treatment and risk harming the fetus. In her words: *"It was an unwanted pregnancy, but as the baby was growing in me, I was afraid that the chemo that I had already had might harm it."* She explained that she was very ill at one point, and believed she was about to spontaneously abort: *"When I was three months pregnant, the doctor told me that at any moment I could lose the baby. (...) But by then I didn't want that to happen, I had become attached to having it".* Lastly, she explains the fear of suspending treatment and of the cancer progressing: *"We stopped chemo and I did the quadrantectomy* (surgery) *while pregnant. Birth was a cesarean, with some complications. But okay, I had to start treatment again, and I didn't know if the tumor had advanced."* (Cássia)

Besides all the obstacles stated, analysis of her report reveals a fear of having an abortion and being responsible for the crime of acting against a new life. She received a medical referral that would allow her to opt for abortion, a right she had by law due to having been through at least three chemotherapy sessions already pregnant, before receiving confirmation of her pregnancy. The treatment could have harmed the already-forming child, which led her gynecologist to recommend going to court for the right to an abortion.

However, the delay between the processes linking mastologist, gynecologist, and oncologist, along with the demands imposed by the court, deepened the moral dilemma that Cássia was going through. She gave up on her court case for the right to an abortion and went ahead with her pregnancy, despite her fears and the adverse circumstances. Her option, she stated, was supported by her moral principles. At the time of the interview, the child had been born and was approximately a month old. And the woman, who had become the mother of a newborn, continued her fight against the disease. Thus, to her routine were added caring for a baby as well as finding milk (bought or donated), as she could not breast-feed due to the treatments she had returned to. Her husband was unemployed, and the social welfare support for illness that she was receiving did not cover their living costs and the expenses of a newborn child. The family's situation was difficult, and they were dependent on favors and donations.

Fernandes and collaborators (2011) revised the literature on breast cancer and pregnancy, finding around 240 international and indexed articles on the theme. After analyzing the studies, the authors concluded that: "(...) there is evidence indicating that gestation does not worsen the evolution of breast cancer, and the bad prognosis is related to the late classification of the tumor." (Fernandes et al., 2011, p. 1) On the other hand, in a revision of the literature by Martins and Luccarelli (2012), breast cancer associated to pregnancy had a controversial prognosis. The authors identified a lower survival rate for women in these cases, as well as obstetric complications, teratogenicity, and other issues that should be taken into consideration. However, they also discuss the advance of treatment techniques, which can ensure a healthy pregnancy despite breast cancer. Finally, it is worth citing Vieira, Gomes, and Trajano (2005), who studied the social representations of breast cancer and the relationship with pregnancy, affirming that the female imaginary associates cancer with death, and pregnancy with life. Thus, in the perspective of the authors, health professionals must understand this phenomenon in order to be compassionate to the women facing breast cancer while pregnant, or who become pregnant during treatment, or just after.

2.4.2 Divorcing from oppression

Another subject identified in this immersion into the process of fighting the disease was the intensification or rupture of intimate affective connections. Most of the women reported that their ties with their life partners became stronger after diagnosis, but the opposite experience took place for two of the women among all the participants of the study. The women who reported that their husbands did not take news of the disease well, and were not compassionate, were also the ones who opted to begin divorce proceedings. From their statements, it was possible to understand that they experienced a greater abandonment on behalf of their husbands, and also heightened aggression within their homes. They affirmed they had taken this decision because they were at a moment in their lives (facing cancer) where they considered the presence and support of their partners to be of the utmost importance in moving forward. However, despite a similar positioning, their stories are distinct: one woman acted to rid herself of the oppression she had lived under for years, and which at that moment had extended to include her children. The other acted on feelings of exclusion, associated to the possibility of no longer being loved.

For Aurora, whose husband appears to have declared war against her from the moment of diagnosis, her marriage was never effectively functional, since to remain married, especially with regard to her children, she had to let go of her own interests and act according to her husband's requirements. According to her report, despite both having successful professions and good social standing, in their intimate lives she sometimes submitted to things she did not want or did not agree with subjectively, just so she wouldn't have to go through a divorce and expose her children to a loss of family structure. She stated that her husband had already hit her several times in the past and had also forced her into sexual relations, either when drunk or when angry, gaining pleasure from subduing her. However, the marriage had already lasted twenty-three years in that format, and, she said, she had told herself for years that she would accept living that way to protect herself and her children: *"He was always bad, he hit me and behaved badly to me since our first daughter was two years old. But I tolerated it for my children and life structure, as I could handle it."* (Aurora) What changed in Aurora's life, from hearing of the disease to realizing she was weakened and fragilized by the treatment, was that the sexual abuse and physical aggression against her diminished until it stopped entirely. However, this violence and dominance started instead to be expressed against their adolescent son and daughter, who were being beaten by their father or threatened with expulsion from home, either for accompanying their mother to her treatments or for sheltering her in their rooms on the days when she felt ill and did not want to sleep with her husband.

Aurora and her children became victims of her husband, who did not know how to deal with the changes his wife was undergoing after beginning her fight against cancer. If before he abused her sexually, once this became impossible due to her illness, he became irritated and expressed his anger through physical violence against the children and psychological violence against his wife. The situation became unsustainable, and the woman could no longer put up with her husband's actions. In her words: "*(...) But now I need care, and what he's doing is worse than abandoning me; for me to be healthy I need peace, and he's oppressing me, repressing my children. The two* (referring to her children) *are taking antidepressants. (...)"* The outcome of this situation was that immersion in the fight against cancer brought Aurora new purpose, and five months after starting treatment, with the support of her children, she decided to file for divorce. She associated this positioning to a need to value herself, emphasizing self-care. She also modified her previous behavior, although her desire to protect her children remained constant. Before, she associated maintaining her marriage to her family's (children's) well-being; later, divorce meant restoring this well-being.

It is important to note that the issue of domestic violence in Brazil is a significant one, especially violence against women, a fact that Aurora, in this study, was actively living with. Guimarães and Pedroza (2015), in their investigation of domestic violence associated to a gender perspective, state that Brazil's chauvinistic and patriarchal culture had legitimized and banalized the different forms of violence carried out by men against women. According to the authors, the Maria da Penha law, which came into effect on September 22 of 2006, is working on suppressing this banalization, although there is still much to be done. Fonseca, Ribeiro, and Leal (2012) note that the biggest issue in domestic violence practiced by a partner against a woman, when physical aggression ceases or is not present, is the prevalence of psychological violence, which can cause long-term psychological damage. Also, the authors affirm that the cycle of violence is fed by tolerance and self-blame, or even by a lack of comprehension, on the victim’s behalf, of how to deal with the situation.

Beatriz is the second case in this study to cite the beginning of divorce proceedings as associated to the experience of sickness. She was married for close to twenty-five years and said she always enjoyed feeling loved, cared for, and desired by her partner, which made her believe she had a happy marriage. However, the situation began to change when she told her husband about the cancer and noted, initially, that he became scared and denied the truth, saying he did not believe her. When faced with a diagnosis and the first treatments, with their side effects, she noticed that her husband was distancing himself, spending more hours away from home. Their children were married and lived far away, and her husband would not help when she was weak and debilitated. He would leave for work and, after, would go to bars or other activities with his friends, leaving her alone at home. She turned to her daughter for support, who started visiting her sick mother daily, helping with domestic chores and self-care, especially during chemotherapy.

However, the final decision to file for divorce, in the case of Beatriz, came from issues in an intimate context, after her husband started demanding she wear a wig to sleep in their bed. Also, the frequency of sexual relations diminished, and she could no longer change her clothes near him, as he declared it was disturbing to see her with a scar on her breast or without hair. In her words: *“Because love conquers all! When you love someone, you’re not going to reject them because they lost their hair. So, if he liked me, it wouldn’t be because I lost my hair that he would reject me. (...)”* (Beatriz)

A broad cross-sectional study, quali-quantitative in nature, was developed by Dorval and collaborators (1999) to investigate the belief that husbands abandon their wives due to breast cancer in Canada. They examined cases of conjugal collapse, seeking to connect them to the disease. The result of this investigation was that breast cancer is not associated to conjugal rupture for couples in Canada, where the study was based. For the Brazilian public, no such studies could be found, in order to measure the relationship between breast cancer and separation or divorce in the country.

Silva and collaborators (2010), who carried out a qualitative study on the perception and behavior of the spouses of mastectomized women in Brazil, reported that men with a moral, emotional, and affective foundation have a higher capacity to support their sick wives than those who do not have this foundation. The authors found men who remained united with their spouses, even as the couple dealt with a diminishing frequency of sexual relations, acting effectively so that the couple's intimacy did not come to a complete end. In one case of the study, the couple's sexual and intimate life ended with the mastectomy, however, no divorce occurred. The authors noted that, in the husband's perception (whose sexual life ended with the mastectomy), the marriage was sustainable due to the friendship they have maintained since.

2.4.3 Finding oneself even when faced with new daily challenges

A crucial challenge in surviving the process of dealing with breast cancer was managing to adapt to new routines. Medical professionals and nurses, for the most part, gave instructions regarding diet, the need to protect the body, the danger of frequenting closed spaces, and use of recommended prescription medication. Even so, all the women participating in the study, in different words, talked about the difficulties of daily life with all these changes that demanded effort from them and from those they lived with.

Dietary discipline, for example, pushed many of the women away from activities they had formerly enjoyed, such as cooking for their families or frequenting birthday parties or other social gatherings where there was food. This favored the enforcement of a partial social isolation, since parties, full of tasty food, became situations they felt obliged to avoid. These restrictions were especially evident with regard to daily diet, which came under constant vigilance to avoid worsening the side effects of chemotherapy or hormone therapy, as well as to improve nutrition. Fatty or overly processed foods were to be avoided, along with fried food and others; on the other hand, vegetable soup, fresh fruit juice, and fiber-rich food were encouraged. To sum it up, in the words of Bianca: *"You have no option, if you choose to live, you have to live with a mandatory diet that's actually fattening, because it's more nutritional than those done for aesthetics. But not everyone understands that, so, it's best to not even go to parties.".* The participant notes that in making a choice, in terms of surviving the disease, it is also necessary to accept the restrictions imposed by the treatment, in this case, dietary.

Regarding this theme, another participant's statement reveals a care not just for herself — following medical guidelines — but for other women in treatment. She clarifies the relevance of dietary care, explaining that this is connected to immunity, a key aspect for the treatments' success:

> It's important to point out to women that fibers, they have to be eaten, because that's what helps immunity. Especially if you don't want to keep doing chemotherapy all your life, you have to take care of your diet. Because it's like this, people get depressed and your immunity gets low, then you don't eat right, don't feed yourself right, immunity gets even lower, like a vicious cycle. (Aline)

For the participants of groups A and B, the challenges in adaptation regarding diet were more connected to changes in habit. For those in group C, the need to add new types of food to their nutritional routine posed a financial burden to their meager budget, often leaving them scrambling for donations. The poorest women in the study had no daily access to fiber-rich food such as meat and certain fruit or cereals. Thus, in order to improve their diet, they were forced to look for help. Sometimes this help arrived spontaneously from relatives, friends, or neighbors: *"Mrs X, she knows the suffering that is this disease's diet, because she had cancer and won. Every day she brings me a plate of food at her house, even if just a good soup, and she even chops up the bits of meat. (...)"* (Cristina). Among the 7 (seven) poorest women in the study, 5 (five) confessed they had to overcome their embarrassment and apply directly to family and/or friends, or non-governmental organizations (NGOs)[7] that support patients with cancer, in order to get the food they needed, when trying to ensure the correct diet. The other 2 (two) women did not need to ask for help as their children ensured they were eating appropriately.

Another topic was exercise, for which only one woman was told to adopt moderation, as she was a regular sports practitioner. For most of the other women, the subject emerged as an obligation, since physical activity was not a regular part of their routine. According to Aline, the only one who practiced sports: *"(...) I tried running, but I was losing my breath. So, I quit. That's when Dr. X told me to take up walking, to walk at my own pace. So, I started to do that and it's going."* Aline used to swim but quit, due to her treatment — both for the risk

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[7] "It is necessary to discuss what are NGOs and what they serve for, considering that public health in Brazil had its services guaranteed by the 1988 Constitution. (...) Thus, we can identify that the Non-Governmental Organizations (NGOs) that offer services to oncology patients are considered Nonprofits by the official organs of the Brazilian government." (Fernandes, 2019, p.19-20) Fernandes (2019) explains that the NGOs that support oncological patients in Brazil are private nonprofit institutions, made up of groups of people who are volunteers or employees, and which are self-managed and offer services to oncology patients, complementing SUS services — when they offer health services. These institutions also assist welfare services, by donating food baskets, fresh produce, clothing, wigs, and wheel chairs, among other items that can be considered necessary for survival or for improving the quality of life of oncology patients, and which are not covered by public services.

of frequenting public pools or other environments that could expose her to contamination, and for the exhaustion she was feeling. She tried taking up running but, as stated, realized she couldn’t do it due to shortness of breath.

Countering Aline’s case is that of Carla, who like many of the women was told by her doctor to take up walking, after the realization that she had become very sedentary and unmotivated due to the impositions of treatment. But Carla wanted to feel well-disposed, and so, felt that the idea of going for walks was pointless, criticizing it emphatically: *“I can’t even walk a few blocks, because I feel weak. I used to like going out dancing, but that was to have fun. (...) How can my doctor tell me to go for walks and have a normal life?! Normal how?”* (Carla).

Carla’s case is not an exception, as most of the women in the study did not like the medical recommendation of daily walks. Many felt this was one more imposition of their treatments, as stated in their interviews. However, a minority among them attempted to follow the recommendation sporadically, having been for walks a few times, something that took effort due to physical debility and lack of habit. A third of the women interviewed did not mention physical exercise at all, either in an autonomous manner or by medical recommendation.

The routine of self-care with skin, mucous membranes, and teeth and gums, was another topic that demanded daily efforts from the study participants. Their eyes and their hairless heads, both in cold and warm weather, also required special attention. Many women noticed that their skin became more fragile and sensitive, obliging them to use creams and oils daily to help reestablish hydration. In two cases, boils appeared on different areas of the body, needing dermatological care. All the women suffered from dry mucous membranes, from their nostrils to their vagina. For those women who were sexually active, the use of lubrication during sex became crucial to avoid lesions in the area. The loss of sexual desire was also a theme present in most interviews — 12 (twelve) to be precise — although not emphasized. Only 2 (two) participants, both single, did not mention anything regarding their sex lives. Only one woman, Ana, affirmed she had not suffered any changes in her sex drive, which made her raise the question of why the theme was always prevalent among her treatment colleagues, since it did not fit in with her experience.

It was noted that some of the women who underwent chemotherapy had to seek dental care for lesions in their mouth and gums. The women also had to take greater care of their lashless eyes, more exposed to the microparticles in soot or dust, and employ eyedrops frequently to clean and protect them. Bare heads required protection against cold in winter, and against sunburn in summer, not to mention the need to shield them from the gaze of others. Nails could no longer be painted and groomed as before, as removing cuticles meant exposing themselves to the risk of infection, due to their lowered immunity. To complicate matters, many women who before had clear nails reported that they became darkened and fragile, full of surface irregularities. One woman joked about it, trying to transmit the absurdity of the unexpected within a real situation: *"All my nails went black and a tooth fell out of my mouth, because everything of mine was weak. Can you imagine it? It's like a character in a horror movie!"* (Bianca)

Leaving home took more of an effort, not just due to the exhaustion that came as a side effect and all the other issues mentioned previously, but because the clothes and accessories they used before no longer worked for their bodies (physical form), which had been transformed by the treatment process. The use of corticosteroids, for instance, was often cited as a cause of bloating and weight gain, leading to a loss of clothing, which no longer fit. For instance: *"Change?!* (in an ironic tone) *Look at the size of this stomach! This isn't change* (laughing, a little irritated*), this looks more like a balloon! (...) I have nothing that fits me well."* (Carolina) A small minority (two of the women) reported losing weight after starting treatment.

The interviews also cited the embarrassment and shame of exposing themselves in public without hair, demanding a search for scarves, turbans, or wigs to protect their image on a social level. As reported: *"There is still the gaze of others on the street, those who look at you sort of sideways, showing fear because you're wearing a turban, because I didn't want to use a wig. A wig would be less noticeable but bothers me too much. But going bald, everyone would look!"* (Antônia)

The female body receives a lot of attention, not just from men, but from other women, as was evident in an analysis of the interviews. Certain aspects are seen as symbols of femininity, such as hair, eyelashes, and eyebrows, as well as breasts and silhouette — which form a figure that cannot show a prominent tummy. The effort to find themselves was also evident in this daily attempt to ensure their femininity, or at least the external characteristics that are socially associated with that image.

Researchers Reis and Grandim (2018) carried out a qualitative study with 13 (thirteen) women who suffered from alopecia during breast cancer treatment. Their findings point to alterations in the self of these women, influenced by their social environment and families. They resort to using adornments such as scarves and wigs to hide their hairless heads. They adopt a posture for this loss of hair: *"A necessary evil that comes, leaves its mark, but* *passes!"* (Reis & Grandim, 2018, p.450). The researchers interpreted the phenomenon through a psychosocial perspective, considering that the participants appropriated the negative stereotypes that accompany the stigma of breast cancer. Alopecia is a social marker of the disease. In an attempt to avoid social exclusion, the women resorted to adornments to hide the issue. However, the social sphere also associates scarves and turbans with the disease, and often wigs are also noticed, as they are different from the original hair. It remains up to the women to refute the negative effects of this stigma. The researchers concluded that support from health professionals for women living with alopecia is relevant, as this is a moment of great suffering and difficulty in adaptation, both regarding themselves, and in terms of the wider family and social environment.

Araújo and Fernandes (2008), in a qualitative study on the meaning of breast cancer diagnosis for women, use the concept of body image, from a perspective of symbolic interactionism, pointing out the relevance of a balance between body composition and the nature of interaction of social actors. In this sense, women have their own histories of body experiences, and of how this body is a mediation tool between them and their social roles. When facing the disease, this body is no longer integrally recognizable, as it goes through all sorts of loss. The sick woman cycles simultaneously through feelings of fear, frustration, and insecurity not only due to the stigma of the disease, but from alterations of the self. So, the challenge of dealing with the disease is one that extends to social relationships, as the woman needs to assimilate her new body experiences in order to interact socially.

In the present study, the participants identified strategies for dealing with their sick bodies that were connected to their socioeconomic conditions. For those in better financial positions, permanent makeup, for instance, was a resource found to replace lost eyebrows, in an attempt to recapture a previous facial semblance. Wigs were also purchased, seeking to replicate the original hair. The women with fewer financial resources, excepting the one who identified as male, said they used eyeliner and eyeshadow (makeup items) in their effort to look like their previous selves. These women were given wigs and scarves from NGO´s and, like the others, tried to ensure an appearance that left them feeling more secure about social interaction. The following segment registers the wisdom revealed by one of the participants:

> My eyes are watering now from the lack of lashes. So, I used to value my lashes for using mascara on them and looking prettier, and now I value them because they were a defense barrier. And I miss them a lot! But there are many things that need to be adapted in my routine. Every day for example, you need to get up bald. It's different from me being here in front of you all dressed, with lipstick, a scarf. Because everything is different when I wake up

> and see myself, understood? You have to put yourself together! This becomes a routine that is different, you have to discover how to put yourself together to be able to live your day and move on. (Ana)

Ana summarizing her immersion in the disease and her struggle to find herself, even if her external body had been modified. In this last report, she states: "*You have to put yourself together*". This led the researcher to a new comprehension of women as a figure that must be set up, constructed, going beyond the process of dealing with illness. Women must first put themselves together for themselves, based on constructs assimilated in the social medium. In this manner, they build an external image worthy of approval in the mirror, and at the same time one that will be approved by society in order to maintain social ties. During illness, a new effort to put oneself together emerges, as it becomes necessary to deal with the changed (or changing) body. This demands, besides an effort to relearn about oneself, an acceptance on behalf of the woman.

Charmaz (1995) cites Gadow to clarify the concept that human existence essentially means embodiment, defining the totality of a human being's self as inseparable from the body it inhabits. And, although inseparable, the authors agree that self and body are not identical, and that a relationship exists between them. This relationship can become problematic, especially for those with chronic diseases who perceive they have suffered body losses, reversible or not. The self does not promptly adapt to the new body it inhabits, as corporeal losses upset this self-body unit. Charmaz (1995) also cites Turner, affirming that the conflicts can be greater if the ill person is young, or if before getting sick they invested in practices to preserve their bodily youth. The meanings of these losses will always relate proportionally to the suppositions and discourses on the body that had been previously adopted by the person who becomes ill.

Kim and Son (2017), who also worked with GT and the analysis of how women manage their own appearances while facing breast cancer, found different categories that caused the women issues, including skin alterations, alterations regarding hair and scalp, and general side effects. The way the women reacted to this — for instance, with behaviors such as choice of clothing, skin care, or makeup — was considered by the authors as action strategies. However, their study, which focused on Korean women, corroborates with this present research in that the biggest problems the women faced were psychological in nature. They concluded that the women suffered the most internally, in the manners with which they dealt with their subjectivity in order to win against the disease.

2.5 Discussing Fears

"What are people most afraid of in this life?" (Aline) the participant asked the researcher. After a silence, the interviewee continued: "*What people are truly afraid of is their own death!"* (Aline)

Fear was a recurring subject in this research: fear of death, fear of the disease returning, fear of judgement from others, fear of failure, fear of disappointing loved ones, and so forth, with a variety of consternations present in the words uttered by the participants. These fears were shared in different tones of voice, sometimes with tremulous words, other times accompanied by tears. In this topic, it was not possible to discern any differences in positioning between women from different socioeconomic or cultural backgrounds, as the several fears were present for all. What could be identified as different, however, is that one of the participants not only feared death, but also avoided thinking about it by making use of sedatives along with the continued consumption of beer (alcohol). She knew this was dangerous and had been informed of this many times, by doctors, her husband, and her children, but she would still escape to a bar near home, before or after taking medication. She reported the experience to the researcher, trying to pass it off as having happened in the past, while smelling strongly of beer: "*Because it was like this, when we're sick we feel like death is closer, so yes I would drink, because I didn't want to think about it or feel it. (...) And there's also the pleasure of a cold beer, right*?" (Clarisse) Paradoxically, to express observation of this phenomenon in a succinct and poetic manner, this woman appeared to seek out her own death, because of the fear she felt that death was coming for her anyway.

Like Clarisse, the other women also spoke of their fears, especially the fear of death. And most affirmed having resorted to different types of help to be able to speak openly of this, such as psychotherapy sessions (specifically: 4 already frequented therapy before becoming ill, and another 5 started attending after diagnosis) or support groups for women experiencing cancer (7 participants). The numbers do not add up to 15 (fifteen), as many made use of more than one resource to discuss their fears. Despite this state of alarm, most of them were hopeful with regard to a cure for their disease, believing they would not die from cancer. However, the idea of a relapse was identified as a continuous and alarming source of anxiety.

2.5.1 Facing the fear of death: many women die, but I have no obligation to do so!

Sometimes, the distress of the participants of the study could be seen when they claimed they were not going to die. It was possible to identify three distinct forms of justification. For most, the discourse used was that they were doing everything as they should, with discipline, throughout their treatments, and that therefore their lives were ensured. Others stated that they would not die because they had faith in God, who would not abandon them. Finally, a minority of the women said they would not die yet because they had to finish raising their children. However, among the women there were some who revealed through their statements that they did not know whether to believe or not that they would survive the battle against the disease.

Each participant brought their own ideas and contributed to the study, but some discourses stood out for the tone of expression or for the simplicity and honesty of the thoughts shared. One of the most interesting social actors, in the researcher's perception, was Carolina. In the following segment, she explains how she felt when faced with the fear of death, and how she tried to obtain from her doctors a confirmation or denial that the treatments would work: *"The doctors only use abbreviations with me, but I don't want abbreviations, I want to know what it's about! They should speak like this to me: 'okay dear, you're going to die, or you're not going to die'".* (Carolina) Her words indicate primarily a dissatisfaction with the communication established with health professionals, but the idea also contemplates a genuine desire to gain knowledge, through the doctors' words, of the real dimension of her risk of dying.

Moving on, it was possible to identify a posture in some of the women that revealed an internal discomfort and moral dilemma, which emerged when they asked themselves why cancer had arrived in their lives. For some, this made evident a strong presence of the stigma of death that accompanies the disease, as well as a sense of punishment, as if sickening from breast cancer was a penance. The words of Beatriz are representative of this type of thought, which appeared in the reports of 5 (five) of the interviewed women: "*Because many times I prayed to God, in those moments when I was most sad and fearful. I prayed in silence to see if I could understand within me, why I was having to go through this* (cancer and the fear of death)*, and what I might have done wrong?"* (Beatriz) In the words of Bruna: *"I always lived in the countryside, I had a natural and healthy diet, I never smoked or drank. Why is there cancer in me? There are so many people who look for death with their own hands, smoking, drinking, and using drugs? I've never looked for it."*

However, most of the women in the study (10), did not mention any self-questioning regarding the *why* of the disease in their lives. Some even appeared to be dealing with the disease in a less stigmatized manner, and instead of a death sentence, were handling the disease as a momentary occurrence that was already being overcome. These women adopted a positioning that focused on the future, and to a certain extent this helped free them from their fears. It is interesting to note that this positioning, for the most part, took place among the youngest participants of the study, with the exception of Ana. In the words of Cristina: "*I face it like this, I am not sick* (as a person), *I am sick* (with an illness). *This is a disease that had a starting date, a treatment date, and will have an end date. So, it's a period, after which I'll have a normal life. All fears, including that of death, are beaten that way."* (Cristina)

The other women, especially those with higher education levels, focused on understanding the disease and the fight against it, even though there were no guarantees of victory, as can be observed in the following segment: *"No doctor spoke to me of metastasis. But I have to trust in God and in chemotherapy. I want to believe that the chemo got it all* (cancer), *and that not one cell escaped and migrated somewhere else. That's why I did it* (chemotherapy), *right?!"* (Carla) Carla revealed her fears of not managing to be cured. In Ana's case, she did not consider herself a former oncological patient, and aimed to think in that manner for a long time, as she did not want to risk lowering her guard against the disease. In her words: "*I can't deny I'm afraid, so I'm going to always be anxious, always on my guard, because it's a disease that makes you go through very aggressive treatments. I prefer not to consider myself a former oncological patient, because that helps me to be always on the defensive."* (Ana)

There is also the fear that others bring with them, and that ends up affecting the sick women. To be socially inserted means generating situations where other social actors do not always manage facts in an assertive manner. Due to the stigma of death that accompanies the disease, many women have to deal with the opinions of friends, relatives, and even acquaintances, who upon learning of their cancer end up distressing them with negative comments. An example of the phenomenon follows:

> (...) So I said it was breast cancer. So, she *(a known)* said: 'do you remember X, that girl who worked at the gatehouse?' Yes, I remember. 'Well, she had breast cancer and suddenly died.' God, I thought, what is this? No subtilty! It's a good thing I didn't take in her ideas. Because people think that everyone who has breast cancer is going to die, and if I go with her ideas, I'll feel obliged to die, but I have no such obligation. (Aline)

The experience of this participant, due to her way with words, was used as the title for this section: *"Many women die, but I have no obligation to do so!"*(Aline) By means of this assertion, the researcher tried to clarify, in a summarized manner, the positioning that most of the women in the study adopted when facing the social actors who, intentionally or not, upset them with negative stories that were full of the death stigma associated to the disease.

Some women proved they were capable of questioning themselves and others, not allowing more suffering to be inflicted upon them. Thus, in the same way that they dealt with the chemotherapy process — adopting either an above average social identity goal, a protected identity goal, or a contingent identity goal —, they also took action when facing other people, defending themselves or not from the negativity that others attempted to transmit. However, some of the participants could not construct the necessary barrier between what they felt and what others felt, and sometimes, despite attempting to defend themselves from camouflaged suggestions that they were about to die, they did not escape these encounters unscathed. The following segment portrays Bruna's experience:

> I have some neighbors, mainly elderly, who started being afraid of me after I lost weight from the disease and began wearing a turban or hat. (...) A neighbor who was almost ninety years old came to me and said: 'X who had the disease died, I'm afraid of this disease because it kills!' (...) 'I'm going to die too, right!?' And thinking of that made me feel terrible. (Bruna).

The women who had adopted an above average social identity, and most of those with protected identities, were quicker to manage negative social experiences and defend themselves without permitting others to bring them additional suffering. Ana's example reveals how she faced a difficult moment: *"So some days ago we had a party there* (at her countryside property) *and people wouldn't get close to me, they would shrink back when they saw me, so I respected that they didn't even want to hold my hand."* (Ana) She explains that the family had decided to hold a birthday celebration for her in the countryside, where they owned a house. They invited people who lived in the area, as well as relatives and friends, to take part; however, many of them didn't even want to greet her. She explained: *"And it wasn't fear of contagion, it's because cancer, for many people, is a death sentence. So, the people who believe that, they put you on the brink of death and they don't want contact with you."* (Ana) The participant's report corroborates the idea of social stigma defended by Goffman (1988) and of stigma of the disease described by Sontag (2002).

2.5.2 The feared recurrence

For doctors, internet sites and different social media networks, as well as friends and relatives and the women themselves, the subject of recurrence is a heated one, as can be seen in the interviews. The feared recurrence can take place with breast cancer, as this is a systemic disease. Pedrini and collaborators (2011) state that even after local treatment (surgery), and after chemotherapy and/or radiotherapy, no doctor can affirm that the disease has been completely eradicated and will never return. The women in the study knew this, with a higher or lower capacity for assimilation, revealing they were aware the cancer could return, and mentioning their fear of metastasis (cancerous cells that spread and can be found in other organs, even those distant from the original tumor).

Salci and Marcon (2010), when researching what it was like to live with the ‘ghost of cancer’, concluded that women who have had breast cancer and their families continue to live in a state of alarm, fearing a recurrence of the disease. This leads to periodic preventive exams, which become routine even for those who have concluded treatment at least five years previously — the stipulated time for a definitive discharge to be considered. These women remain on alert, seeking medical attention for any changes they perceive in their bodies. The researchers concluded that fear of metastasis, or of recurrence, becomes a “(...) “ghost” that haunts the life trajectory of these women and their families.” (Salci & Marcon, 2010, p. 24)

Rees (2017) carried out a study based on GT and concluded that in women under 45, the fears about cancer are greater, including the fear of recurrence. For these women know that they will still live for many years under constant checks, in the shadow of a new discovery of the diagnosis, even though they have been treated and have recovered from the disease.

A few excerpts follow, extracted from interviews from participants in all groups of the study, representing fears that touched them all. Once again, it was possible to identify that socioeconomic contexts influenced the women’s perceptions, even when considering the scope of recurrence fears.

For the participants in group A and for Carla, their own studies and/or education levels, besides the aforementioned connections with relatives or colleagues working in the medical area, were added to research carried out on internet sites or in books on the subject of cancer. These elements were decisive factors in broadening the fear of recurrence that was present in these women’s lives.

Carla was saddened, unmotivated for her treatments and insecure as to her future. Several times during the interview she claimed to be afraid that she might have a metastasis and had possibly discovered her cancer too late. In some way, she blamed herself for this, for spending three years without a mammogram. However, as the following excerpt reveals, she was aware that the specific cancer she was diagnosed with is hard to detect. Additionally, it seems that her reading and internet research on the subject of metastasis risks had built up her insecurity. She was fearful as to how long she had ahead of her to live, and her words reveal this anguish:

> I spent almost three years without doing a mammogram. Then people go and tell me: 'But you discovered it in time!' I don't know if I discovered it in time! I don't know if I still have time! In truth, the cancer I am facing is hard to detect. And my greatest fear is this idea of invasive cancer, you know it can invade other cells, right!? You know about metastasis, right? I read it all on the internet. I read that invasive cancer can migrate even to the brain. My biggest fear is that it might have already invaded other organs. So, in each exam, each ultrasound, electrocardiogram, I feel tense, because of that, you know? I'm afraid of a metastasis. (Carla)

Ana and the other group A participants also revealed a fear of recurrence, especially due to what they had read and researched about their specific diagnoses. However, these women were convinced they had discovered their cancer in time for a possible cure; they were clear about this. Also, they believed more than Carla that they would be cured by means of their discipline with treatments: "*But I take my precautions, for example, I stay more inside the house to avoid catching anything, because I know my immunity is low. I also keep warm, not to catch a cold (...). And I'll be cured, because I do everything the right way and I discovered it in time. (...)"* (Aurora). For Ana, the most important thing besides ensuring a cure at that, was acting preventively in the future: *"Time will pass, and I will still do exams, first twice a year, and then yearly (...). But you're always going to have to go to the oncologist, and they're always going to ask you for exams to see if the cancer hasn't returned somewhere."* (Ana)

To represent the women in group B, the first segment reports how the participant acquired knowledge about the disease she was facing: *"My daughter is a nurse with higher education, and she told me how this cancer is and how it can be dangerous, especially with the risk of metastasis. She tried not to frighten me, but it was inevitable".* (Bruna) The other women in group B either had no relatives working in health care, or did not mention them, basing instead their fears of recurrence on knowledge gained through reading or from conversations with friends and acquaintances who had been through the experience. As one woman clarifies, she changed her understanding of the problem when talking to a friend who had already faced the disease and shared her experience, alerting her about recurrence: *"So my friend said: 'Do all the treatments, don't believe you're cured just because you removed an entire breast. Cancer can hide in other cells and return someplace else'. That made me stop saying I was well, just because I had already been operated. (...) I have to wait until the end."* (Brigite)

Cláudia's words are an initial representation of group C: *"Look girl, now it's an issue of insecurity, right? We're afraid of not being cured, but after we confirm we're cured, then… Well, then I'll feel very well indeed!"* She reveals a fear of not being cured after the treatment. Another in the group said, in a similar manner: *"For me, my biggest hardship is this, I think of my children, I can even say I'm well, but we're afraid of the disease returning, because we know it can happen."*(Camila) Both women reveal a fear of recurrence, but while one associates it to her fear of feeling well with herself in the present moment, the other sees it as her biggest hardship during the process, especially as she wants to survive to care for her children. However, neither one described how they found out about recurrence risks, which raises the question: had they acquired this fear through the speech of other social actors, or of doctors? Like the other women in group C, they had low educational levels, and their reports did not suggest reading or research habits. This leads to the assumption that for them, as with the other participants in this group, the subject must have — in addition to being discussed during medical appointments — been fostered by the stigma of the disease that is diffused in the social sphere. This is corroborated by Carolina, who was very distraught, wanting to understand what metastasis was and how it was significant in her own case (since she would have to undergo new exams):

> Let me ask you... what's your position? What are in your opinion the types of cancer? What is metaphor? What does metaphor mean? *(asking the researcher, who answered: Metastasis? Are you asking me about metastasis? Has someone talked to you about this?)* Yes, that's it, that's the word! So... like this, more or less. Because it was written in my exam results, but then I asked the doctors and they didn't explain, or if they explained, I didn't understand. (...) So, like people say, so I think it's like if it was an egg, and then the egg broke and the things in the egg came out and are outside the egg, in the blood stream. Because honestly, it was breast cancer, right?! But now they're asking for an exam of my liver, of my head, and I'm waiting (...). I don't know where this will lead. (Carolina)

2.5.3 Strengthening yourself, strengthening others

An interesting phenomenon noted in this research was the existence of support networks among women who had personal experience with breast cancer. As explained by the interviewees, these were formed by those who were actively undergoing treatment as well as those who were already at the stage of preventive/monitoring appointments and exams. The networks also counted on participation by women who had already been through all of these stages and were free from the disease, but still wanted to keep contact with the others.

Some of these support systems existed informally, emerging as women sought each other out to exchange experiences. They met in small groups, either during treatment, or simply connecting to each other after hearing someone had already had, or currently had, breast cancer. Other networks were more formal, with scheduled support groups run by the women themselves, and in some rare instances with participation by health professionals. The purpose of both types of network was the same: to create a sheltering space, where participants were assured understanding by those who had experience of the disease. What is relevant about this topic is that women discovered they could find mutual strength, either through exchanging their experiences or by creating a listening space where they could be heard.

Two of the women interviewed for the study, one from group A and one from group B, had joined forces with others to start a support group, which began with 5 (five) women experiencing the disease. According to the reports, two months after the first meeting they already had over 20 (twenty) participants for this group, which they named “A New Tomorrow” (Um Novo Amanhecer — UNA). The name was based on two tenets: the first was a shared fear, known as *“the fear of the darkest nights”*, as the participant from group A explained. She went further, talking about how this fear is linked to a certain helplessness at times, when women don’t know how to guide or conduct themselves. Thus, *“a new tomorrow”,* as she said, *“means the light”* of shared knowledge to move ahead. The second reason for the name is that the acronym formed by the initials, UNA, forms a word in Portuguese — unite — with a meaning of association and togetherness. According to the founders, breast cancer pushes women into isolation, and thus they need the support of other women who have the same disease or who have survived it. In their perception and in that of the other 7 (seven) interviewees who had taken part in similar groups or networks, this isolation takes place when women attempt to spare their families from their biggest fears. Another reason they identified to explain the need for these groups was that the women felt that those who have not lived with breast cancer do not understand their experiences in depth. In the words of one of the founding members, whose fictional name will be preserved:

> But you know, the ones who really understand your routine are those who go through the disease, and even though I talk about it to my partner or my mother, it isn't the same thing. So, when you talk to the others you find strength, and it was because of this that I had an idea of creating a new project, that we called A New Tomorrow (UNA). This is a group that brings a routine to the patients and ex-patients, where we set up meetings at least every fifteen days, not on WhatsApp, but personally, so we can talk, exchange ideas, find out what everyone is living through. Because that's when you strengthen yourself, while you are strengthening others. (...) (participant from group A)

Some of the discussion topics in these groups, according to those who frequented them, included: sex life and sexuality, partner rejection, financial burdens, time off from work, family conflicts, diet during chemotherapy, fear of death, fear of recurrence, and myths and truths about the disease, among others. In the words of the other founder:

> It's the nights that bring fear, anguish, uncertainty. You look inside yourself, and look at your family around you, and there's a lot you can't tell them *(the family).* And this is distressing… There are many patients who talk about this, this darkest night, and then what you long for is a new tomorrow. And this new tomorrow can be the diagnosis of your cure, it can be a satisfactory result for surgery, a better result after chemotherapy; and not just that! This new tomorrow is the lightness you feel when breathing in life again, one day after another, so we seek to embrace each other, we seek to find each other and share this lightness, sharing and bringing to other patients that you need to breathe in life, and it has to be light, even when dealing with cancer. (participant from group B)

As participation in these support networks was something that over half of the participants experienced — 9 (nine) women, distributed across the three groups in the study —, the phenomenon was clearly an important support strategy in the fight against the disease. The smallest proportional participation was from the women in group C, since 4 (four) did not mention this theme. Within these the support networks, participants acquired knowledge and also the freedom to discuss subjects that were hard to bring up with family members, either due to a fear of hurting them or to embarrassment; for example, when talking about issues relating to death or to sexuality.

2.6 THESIS: taking all that is WOMAN apart and resignifying existence itself

The struggles of the interviewed women, especially in dealing with their bodies, which were marked by subtle and undesired changes, as previously discussed, brought strain and suffering to their lives. Some of the main changes mentioned were hair loss, weight gain or loss, and loss of the breast or part of it, among others such as eyebrows, nails, and eyelashes. Alterations in these components of the physical form impacted one of the pillars that ensured the women's identification with the feminine figure and with their social roles. Added to this were mood swings and other psychological aspects, most of which were associated to side effects of treatments. In addition, there was a fear of the disease, fed by the stigma that they brought with them or absorbed from social interactions. Once the complexity of the experience is outlined, it is possible to begin understanding the estrangement that women with breast cancer feel in themselves.

From this point on, it is possible to construct a theory, based on the study, that women are taken apart, both in a physical sense and in their psychological aspects, situating them within a true process of subjective change. If a woman can be — symbolically speaking — taken apart, it's because she was once put together, as she was not born with long dyed hair or painted nails, and the curves defining waist and hips, as well as the breasts, only began shaping up after puberty. But beyond biological aspects, there is a social displacement that accepts and validates what it is to "have" a woman's body. Thus, many women go to tremendous effort to reach and maintain certain standards of physical measurements or other characteristics determined as "feminine". For participant Beatriz: *"A well-valued woman is well-cared for, with all the paraphernalia always renewed"*. Later, she explained paraphernalia as the complements that women use to make their bodies more beautiful, such as painting their nails, dying their hair, and using nice clothing, besides staying thin.

However, many of these things that women share as aspects that they carry within, simply by being women, are in truth — to use the participant's analogy — just the paraphernalia they have amassed unto themselves. The word paraphernalia has three meanings in the Priberam dictionary*: "1st) Set of goods for personal use = belongings. 2nd) Indispensable equipment for the functioning of a thing or a determined activity. 3rd) Set of objects considered old or of little value."* (Priberam, 2013, p.1). In this sense, the first and second descriptions for the word paraphernalia can be extended to the values accrued to the body after years of investment, such as long hair that has been straightened, often chemically, or dyed, and breasts that are often molded by bras or enhanced with silicone. Other items like eyebrows, plucked and corrected, or nicely painted nails that are long or have been added to with gel, become the personal goods of each women, forming her own personal paraphernalia. And, to continue making use of the term, this time focusing on the second definition, all these 'belongings' become indispensable for the social functioning of the female human being, in order to carry out the social role of being a woman. The third definition of the word mentions old or worthless objects, which in this case are the same ‘belongings’, the same components of the women’s figure, that had their physical characteristics broken down by the disease. Breasts, hair, eyebrows, and “non-standard” measurements are enough to undermine the conditions that weave together self and body; conditions that are linked to the functions of identity. In addition, it is necessary to consider the exhaustion and the physical and psychic discomfort that also affect these women.

None of the aspects mentioned previously were considered unimportant for the women interviewed, as each in their own way was saddened by the changes they were going through. Even the participant who identified as male suffered this estrangement, in different aspects, such as breasts (one of which became deformed with the disease), stomach, which grew in volume, and hair, which fell out; all of which brought dissatisfaction:

> Because when I was young, I wanted to rip it all out *(breasts)* and get a tattoo, do weightlifting, and be able to use a t-shirt, but now, now it’s not because I want this! It’s because it’s all ruined. (...) Because look at the size of this stomach, and with no breasts, this is going to look so ugly! (...) Look at my bald head! *(removing cap and swiping a hand across her head)* I look like Casper, the ghost! My hair looked like Wesley Safadão *(a Brazilian male singer).* It was all the way to here, (*showing her shoulders*), really big, and in ringlets! And now I look like Cebolinha (*the character Jimmy Five*) from the comic books... *(tears fall from her eyes).* (Carolina)

If previously she desired to look more masculine, wishing for a mastectomy and tattoos so she could wear t-shirts, now she alleged she no longer wanted that, even though she knew the procedure was necessary. She feared she would look ugly without the volume created by her breasts, or worse, the volume from a single breast, as her body had changed with treatment and her stomach was prominent. She also cried for her previously long hair, full of ringlets, which she had been cultivating for a while, using as reference the look of a popular Brazilian singer. Carolina’s experience suggests that not only the social actors identified by a woman’s social roles suffer from the process of breast cancer treatment, but also those who identify with a male social role. Carolina no longer recognized herself in the body she inhabited, feeling lost and without aim with regard to her self-reconstruction.

For the remaining interviewees, all of whom socially identified as women, it was important to rediscover something in their own subjectivity that would ensure their femininity, allowing a female identity bolstered by a certain independence from corporeal aspects, since the physical paraphernalia from before was now, in a sense, useless.

2.6.1 Understanding the body as a social construction and the role of vanity within this context

Women are not born vain, or aware of the social function of their hair, eyebrows, and eyelashes, or even of questions of sexual attractiveness measured by their breasts and other body parts. They learn, mostly from other women within the different social environments in which they develop, to value certain aspects of the feminine body. In certain situations, or in specific moments, although in a smaller way, this learning process is helped along by interaction with men. While learning the value of certain characteristics, women also develop the capacity to implement what they have learned, according to the tastes cultivated and filtered during social interaction. And although the process of human development does not stop, living through the abrupt changes that pervade this body constructed over the years appears to be overwhelming. The women in the three groups of the study reported similar experiences in terms of the social construction of their bodies, with no socioeconomic factors standing out in this process. However, it could be noted that the women in group A had a certain critical posture, questioning the social standards they had followed in order to reach physical beauty. On the other hand, the women in groups B and C, for the most part, had previously attempted to reach these standards without much success, but also without questioning their own conduct or goals. And some continued in this manner, worrying, for example, about how to regrow their hair, even though they were still recovering. A few reports and discussions follow, for a better comprehension of these phenomena.

> Women today are looking for, not all of them, but most, that magazine model's body. It's always been this way, I remember my mother commenting, my aunts, they all wanted to be thin! But today it's a lot, this *(valuing a thin body)* is a lot more... *(Women)* want to be thin and the thinness in magazines today is a lot more. It's not my case, I don't have this worry. Being healthily thin is fine. (Antônia)

On being thin: Antônia noted, in this segment, that in her childhood and youth she would hear her mother and aunts talking about their worries regarding diets, and also about the importance of women being thin. She believed that valuing being thin is something that has always existed among women, but called attention to the present day, saying that magazines present a standard for the feminine body that is even thinner when compared to past standards. She clarified that *"the thinness in magazines today is a lot more"* and believed that this is the standard — "*magazine model's body"* — that most women want to follow.

Finally, she stated that this is not her case, opting for being thin according to healthy standards.

Another study participant, Cláudia, is a 65-year-old woman who had been through bariatric surgery, having undergone a gastric bypass with the aim of losing weight. She was planning cosmetic surgery on her abdomen and breasts when she found out she had cancer and was obliged to cancel the procedures. The participant reported she had never felt good about herself due to her weight, which improved a little after her bariatric surgery. However, she still considered herself fat. Cláudia believed this to be common — that no Brazilian woman "*likes to be fat*" — as can be seen in this excerpt:

> No, girl, I don't like my body, because I was always very fat… *(laughter).* I never liked my body! But after I did the bariatric surgery, I started to lose a bit of weight, and I think I was taking better care of myself. But that was four years ago. So, my dear, that's why I don't have a good relationship with my body. Right? (...) Look, this is a thing of Brazilian women, for sure! No Brazilian woman likes to be fat. (Cláudia)

Trim waist: also, within the theme of being thin, although a more specific concern, is the preoccupation with stomach and waistline. For some women, having a trim waist is what marks the difference and makes a feminine body attractive. They believed that women who take care of themselves can have a prettier body than those who do not practice sufficient self-care. It is interesting to note that, among most of the women interviewed, a high value was placed on surgical procedures, which were included on the list of self-care practices, in contrast to sports, which were disregarded. Reaching an ideal, for many of the interviewees, was explained as "a vanity of Brazilian women", an expression repeated in several interviews. In the opinion of many of the women, vanity would be the guide in this search for the perfect body. In the words of Beatriz:

> I'm going to tell you the following, I think that Brazilian women are like this, beautiful and vain, right?! And for a long time in my life I had a complex, a very big complex, I thought I was ugly, and I didn't like looking at myself in the mirror. *(What do you mean, what was this like? — asked the researcher)* I didn't have a waistline the way I wanted, it wasn't trim enough, and my breasts, after I breastfed, were no longer pretty, my stomach was already large; that would sometimes send me to bed, depressed! Because women need to feel good about their bodies. (Beatriz)

As the participant made clear, she had already been depressed in the past, as she had gained weight, especially after maternity, losing her defined waistline and with a larger stomach. She reported having a "*very big complex*", stating that it was her dissatisfaction with her body that brought her worry and sadness, culminating in sending her to her bed as if she were sick; what she termed being "*depressed".* She continued, explaining further what she called a "*complex"* (suggesting these were body image issues), and how this got to the point of causing her distress: *"It was like this, I had already noticed that women observe other women more than men observe women; so it was observing other women that I noted I was not well. (...)"* (Beatriz) The comparison she made between herself and other women, through observation, let her know her body was not within the standard measurements. This process of observing others gave her the parameters to judge her own body: *"For example, when we go to a party, if a pretty woman arrives, with a nice body, a small waist, her hair all dressed up, her clothing too, then she's the center of attention! Everyone looks at her, because she's like that, a harmonious ensemble."* (Beatriz).

In sum, Beatriz's words point out that the female body is given social value, not just by men, but mainly by other women. Thus, women assimilate from the social, in a continuous process of comparison with others, the definition of what is an adequate body, *"a harmonious ensemble"*, and simultaneously they judge if their bodies are adequate, in terms of measurements. Vanity would be the feeling that gives women the impulse to attempt to achieve the standards they look up to. As this is not always possible, dissatisfaction surges, which can cause self-acceptance issues, as can be seen in the words of Cláudia (on being fat) and Beatriz. For Antônia, being thin was considered important, especially in terms of ensuring health. She wasn't interested in following the ideal of a *"magazine model's body".* Camila, in partial agreement with Antônia, points out the impossibility of having a perfect body: *"(...) I need to get thin, because the doctor forbade me from gaining any more weight. I'm fighting to lose weight, but I think that for many people it's just vanity. How women deal with their bodies is, in my mind, silly. (...)"* (Camila)

Hair: for some of the participants in the study, hair came first as signalizing a woman's beauty, even before body measurements. According to Aurora: "*The Brazilian woman, I think for her, hair is a very important thing, body not so much, but hair… Because you see how everyone changes their hair, and its characteristics, because hair frames the face."* Aurora mentions that Brazilian women "*change*" their hair, and its "*characteristics*", meaning they change hairstyles, color, texture — always in search of a new way to frame their faces. From the perspective of another participant, Antônia: *"(...) hair, it's an important thing for a woman, for her look, for her vanity. Hair is part of a woman's vanity, so this* (referring to loss) *is the most difficult.*" (Antônia). And confirming these opinions on hair, Bianca talked about how she cared for her locks before the disease: *“My hair was down to my waist* (showing the old length with her hands), *and it was chemically straightened and dyed black, because in reality it already grew in white.* (...) (laughter).*”* (Bianca). It is interesting to note that at the time of the interview her hair was blonde, curly, and shoulder-length, which shows how she changed her appearance, wearing her hair closer to its natural style (without resorting to the hair straightening process). She laughed at herself, as if she had imagined her former image, and had simultaneously realized how opposite it was to her current look.

Additionally, one of the study participants introduced a different aspect of hair. For Ana, besides hair contributing to the face’s beauty, it also functioned, as did breasts, as an important component during sex, receiving the partner’s caresses:

> Because lying next to him, in intimacy, you sometimes feel your partner searching. Sometimes he seeks out your hair, and sometimes that can hurt you. You feel he’s there, stroking your head, and that he’s searching… If you don’t have a good psychology, that will distress you. (...) Because my partner helped me a lot, and as for me, I handle it, right?! When I see he is searching for my hair, I try to focus on something else and not think about it. (Ana)

Breasts: some participants spoke freely about their breasts, and about how these organs were important in their sex lives, if they enjoyed breastfeeding or not, and so forth. Others were more cautious in their word choices, revealing a certain timidity in talking about the subject, especially with regard to sexuality. However, they all mentioned caring for their breasts since puberty, when they learned — mainly from their mothers and/or sisters and friends — that they should wear a bra to support them and to conceal the way their nipples stood out. For them, breasts were a focus of male attention, organs that instigate attraction and desire from the opposite sex. In the words of Cássia: *“My friend X says I have little vanity, that I don’t even care about lingerie. But I grew up different from them (*friends*), because I was adopted, and I didn’t learn certain vanities. I only got my first bra to hide my breasts from boys and men. (...)”* (Cássia). The participant explained that she had never met her biological mother, and grew up in a family that only had sons; her adoptive mother was elderly, and had no interest in *“things of girls and women”,* and she associated this to the fact that she didn’t care much about her intimate appearance, in terms of the lingerie she used or what her breast surgery scar looked like.

Most reports also mentioned self-examination as a self-care tool learnt many years before, mainly at primary care centers (for the older women) or at school (for the two youngest women in the study). According to Brigite: *“(...) So, but I didn’t marry and was not a mother. However, I learnt from the doctor at the clinic* (primary care center), *that I should* *take extra care with my breasts, because not breastfeeding was a cancer risk. So, I learnt to do the self-exam there, many years ago."* (Brigite)

It is interesting to note that some of the women mentioned a desire to add silicone implants, even before they became sick: *"I always wanted to put silicone, to be more attractive, because I was very skinny. But I had no money."* (Carla) Others wished they could have removed part of their breasts, for a better physical balance, and this positioning could be found even among the eldest in the study: *"Because after I became a widower, I thought it was better to have the bariatric and plastic surgery on my breasts and tummy, to see if my self-esteem would improve."* (Cláudia) Most of these women said they had never had breast surgery due to a lack of money, and not a lack of desire. Few of them were happy with the shape and volume of their breasts before cancer, and most wished for change. Once again this points to a search for socially acceptable beauty standards, which also include breast size. One of the few exceptions was Cristina, who claimed to be satisfied with her body. According to this segment *"... the way I am, is fine for me..."*:

> I always say to the girls, my friends, some seek perfection, others not so much! I'm at peace, the way I am, it's fine for me! I'm going to do a radical mastectomy and I'm going to try and do an immediate reconstruction, but if I have to be a while without breasts, I'll be fine with it, because I believe there's a resource for everything nowadays! (Cristina)

However, Cristina's satisfaction had certain conditions: her existing body and breasts. She had not yet undergone surgery and was already imagining an immediate or future breast reconstruction. When she emphasizes *"(...) there's a resource for everything nowadays!",* she refers to the fact that, in the past, losing one's breasts might have been irreversible, but not in the present day, where breast reconstruction is covered by the Unified Health System.

None of the study participants said they felt less of a woman or that they were insecure regarding their role as a woman, when discussing their surgery scars or the removal of the breast. Most appeared hopeful with the possibility of doing plastic surgery and finding the desired balance between both breasts, and between breasts and body as a whole. Some even talked about tattooing an image to represent the nipple. The women's complaints regarding their surgery scars were associated to being upset by the discomfort shown by others, with two women mentioning the distress they noticed in their spouses' attitudes, and one lamenting the reaction of her young grandchildren, who saw the scar and became frightened. Finally, one among the three (3) interviewees who underwent a mastectomy was suffering greatly, not from the scar, but from the imbalance in her body weight, due to the size of the remaining breast.

Finally, in Aline's report the participant tried to clarify how she felt about the scar that remained after surgery, saying that *"this is a mark, not a 'scarlet letter'".* She wasn't upset at losing part of her breast, but did not deny that a mark had remained, registered upon her body. However, even though she thought it might be different for those who had a radical mastectomy, she was surprised at the reaction of one of her treatment colleagues who saw the procedure as an opportunity to "*gain life*":

> But there's a difference between mark and mutilation, because a cut is a mark. (...) But it's funny because I was talking to a woman who removed her whole breast, went through mutilation, but to her this was not a mutilation, it was the removal of a disease to gain life. So for me this is a mark, not a 'scarlet letter', but it is a mark. (Aline)

2.6.2 Overcoming hair loss

For the women who were able to accept their hair loss, the treatments and their side effects lost some of the intensity of their more threatening aspects. They appeared to have managed, explicitly or not, to adapt their identity goals to the moment and the experience of becoming ill, as discussed in this subchapter. Some of the things that took place were seen as advantageous by these women, and even the experience of a bald head brought some gains. A small number of the women did not manage to free themselves from this sense of loss and remained immersed in the suffering of disfiguration, not knowing how to manage a new identity goal — this, however, will be discussed in the next subchapter.

Antônia, like the other women who lived through the disease process by adopting an **above average social identity**, described a useful side to the loss of hair, such as economy in shampoo use and the practicality of not having to brush or comb it. This conduct appears to have been adopted in order to render the new reality less catastrophic, since it would be a long time before regrowth:

> So I even thought it was super practical, and I talked to some of the patients who were there *(at Cetus, during treatment)* and who were upset at their hair, I said: 'look, for me this is super practical, it's easier to have a shower, you don't need shampoo, you don't need conditioner, you don't need to blow-dry, you don't need to dye or to brush it!' It's a moment of pure detachment, it's very practical… Apart from the cold, right?! It's just the cold that bothers me. (Antônia)

The posture of Antônia and of others, notably Ana, Aline, and Bianca, recognized by the researcher as people facing illness by means of an **above average social identity**, revealed that they not only dealt well with the suffering of being hairless, but also tried to share their thoughts with treatment colleagues, in an attempt to help them stop worrying about it and feel a little better.

The women who appeared to have adopted a **contingent identity goal** oscillated between ease and difficulty in dealing with hair loss and body changes. Beatriz, for instance, started to see a light at the end of the tunnel when her new hair started to grow. From that moment on, she reacted with positivity and hope for the future; before, she was sad and fearful. She said that when she was completely bald, she could see herself on the brink of death: *"(...) when I looked in the mirror, I thought I was already going to die. I stopped looking in the mirror so I could go through with the treatments until the end. (...) As you can see, together with my hair, my hopes have been reborn. (...)"* (Beatriz) Camila and Aurora, with a similar posture, were joyful at the regrowth of their hair and spoke of how much more hopeful this made them feel. These women associated the new strands of hair to a sign that they were on their way to a cure. However, these two, different from Beatriz, did not lose hope previous to this moment: Camila sustained by her love for her children, and Aurora by her love for her children and her faith in God. In this group of those with contingent identities, there were also two women, Clarisse and Cássia, with a completely different positioning, which will be examined in the next topic.

Finally, the women who were identified as dealing with the disease through a **protected identity** had a wide diversity of experiences, which are worth detailed consideration. For instance, Carolina was a social actor who considered herself male, while Bruna, was a social actor who considered herself to be pretty and attractive before she became sick. Carla, before the disease, considered herself to be an excellent health care professional, but an ordinary woman, not particularly attractive. These three participants did not manage to overcome their physical losses, especially the loss of hair, and were completely overcome by suffering at the time of the interview, which will be discussed in the next topic.

Cristina had a family history of breast cancer, and as she had seen her mother and maternal aunt lose their hair and then regrow it, as well as gain weight and lose it again, she said she was *"at peace"* regarding the transitory nature of the proceedings. She was bald, but certain that soon she would again have hair, as well as reconstructed breasts. Cláudia, on the other hand, despite being an elderly woman, was motivated to reach a new body standard (to be thinner), and thought that the disease treatments were helping in this goal. In her interview she mentions that her hair had already regrown, and that being ill during chemotherapy had taught her to eat with more restrictions. Brigite, on the other hand, who was not particularly vain, was very religious and praised God for everything, including the suffering she was experiencing. She considered everything to be an atonement — her hair had not yet fallen out but was about to: *"I'm not sad, I give praise! God gives the doctors knowledge. All of this is for God. He has supported me in this sadness and pain. I am thankful to God for this salvation, and my trial was to overcome sadness. If my hair falls out, it is of no importance."* (Brigite)

2.6.3 Succumbing to diagnosis by lack of questioning

It is necessary to return to the previously discussed concept of identity goals, which accompanied the women's process during illness, in order to take a closer look at those who succumbed to their suffering. Some of these experienced the process by taking on a contingent identity, while others adopted a protected identity, as mentioned in the last item.

Clarisse's experience opens this discussion, followed by what took place in the life of Cássia, both using **contingent identities**. The first, from the moment she suspected cancer, went into a state of panic and sorrow, which she appeared to have sunken deeper into after chemotherapy. It all began with the conflict between what her neighbor was telling her, about the possibility of having cancer, and what her first doctor said — that she did not have cancer. Life, for her, got darker and darker, and with the confirmation of cancer, she had to deal with chemotherapy and hair loss, which was something that she missed *"immensely",* as well as all the other body changes: *"Because I liked it* (hair), *I liked to brush it and braid it... So what bothers me is that, I weigh even more, because I was already a little chubby, but now my stomach is fat and it's very sad...and I miss my hair immensely."* (Clarisse). All of this was made worse by how ill Clarisse was feeling, as several times during the interview she mentioned not being able to breathe properly, even using anxiolytic and antidepressant medication:

> And I always felt I couldn't breathe, a horrible thing, and now I even got some patches on my body. I feel very sad, I don't want to go out, I don't want to do anything, and before I was cheerful, before treatment I didn't feel this sadness. I already took Diazepam, a few sedatives, right? But now I take Sertraline and they told me it was for this sadness, but I don't see any difference, I'm sad just the same. (Clarisse)

This woman did not manage to ask herself any questions, and did not reveal a comprehension of the processes that led her to anxiety (despite stating she already took anxiety medication before her cancer diagnosis) or even understand the possibility of depression, simply naming ‘sadness’ the feelings that emerged during treatment. She expected resolution for this sorrow simply through her new medication. Also, she did not recognize — or said she did not recognize — the danger she placed herself in when she took medication and drank alcohol. She began to isolate herself, avoiding friends and relatives, because she didn’t want to be seen by anyone without hair. She was living at her daughter’s house, in the city, but she didn’t form any connections with other women who were dealing with breast cancer (support networks). It was noted that this woman saw no future perspectives for herself and was stuck in the moment and full of complaints.

The situation of Cássia was different from the others, as she was pregnant while undergoing treatment. Because of the medical discourse she was subject to, she developed a fear of having fallen behind on chemotherapy, and thus being at a higher risk of dying from an advancing cancer. However, Cássia never complained — not about losing her hair or about body changes. She was worried about her lack of money, and about supporting the baby, but she did not complain. She spoke softly during the interview, her gestures were calm, her movements slow and morose; everything pointed to a depressive state. This woman’s issues appeared to be linked to a lack of strength to ask questions of her doctors, her husband, and at times even her friends. She would keep all her fears and distress to herself, and she couldn’t see a favorable outcome for her life — what she called holding onto the “*will I?”*. And despite questioning herself constantly, as she told the researcher, she couldn’t identify possible paths forward. She was unable to recognize that her complete despondency could be due to the fact that she was always answering other people’s demands, and did not know what she wanted for herself. She had sought help from a psychologist at an NGO, but had not yet managed to escape the “will I”:

> but I started thinking, from the first diagnosis I got thinking ‘will I’... Will I live? Will I face all of this? Will I reap tomorrow what I’ve sown today? Will I be here? And every now and then, even today I have this uncertainty. *(Profound 50 second silence)...* (...) (Cássia)

The next women to be discussed are those who experienced illness with a **protected identity goal,** with a history of succumbing to the disease and the suffering it brought. We will start with Carolina’s story, and then move onto the experiences of Bruna and Carla.

Carolina, as mentioned several times previously, was horrified by her breast cancer diagnosis. For her, the disease brought forth a sort of confrontation with her sense of self, which identified as male. In her mind, and in her words, *"(...) this was a woman's disease (...)"*. In addition, the treatments brought weakness, discomfort, outrage, and a complete shutdown of her life. All that she wished for was to be strong enough to go back to work and continue her former routine, as a *"strong man"*. In her words: *"It makes me angry to speak of it. This is not a sickness of God, it's of the devil! I'm not going to say I accept it because God sent it: 'my daughter, you will go through this!' That's the sort of stuff that those obsessed people keep saying. (...)"* (Carolina) She criticized the idea that acceptance is a duty of religious people and of those who have faith in God (as in her case), saying that those who believe in this are *"obsessed"*, also that she was angry at having become ill with a disease of the *"devil"*. She also missed her hair, and feared mastectomy, something she had actively desired in the past when she wanted a more masculine body. Her suffering was deepened by the side effects of chemotherapy and, in her statement, this took precedence over any fear of death or of being operated. The fact that she associated chemotherapy with all the weakness and discomfort she felt, obliging her to stay in bed at times, made her start refusing to attend sessions:

> my girl *(calling her partner's attention),* this is how I am, she said she's a psychologist, and I'm opening up, because this is how I am! I'm going to say this thing is bad *(cancer)* and it really is, don't put yourself in my place and don't keep telling me off! *(Talking to her partner, who was watching her disapprovingly).* I handle myself; I'm handling it! I'm handling it while I can...Just like I said to her *(pointing to her partner),* I'm not going to do any more chemo. And I said it, so I'm not doing it anymore! I get there *(the hospital)* and they *(the doctors)* can do what they want with me, they can cut me up and turn me around, but that thing *(chemotherapy)*, I'm not doing any longer. For example, it's been over a week that I did it, right?! And that thing, I'm angry at it! I've been feeling ill for over fifteen days… And the woman said it was a few days, but it's been over fifteen days. (Carolina)

Carolina's partner stated to the researcher that she had more than once missed a scheduled session, and in this manner was delaying her treatment. Both were suffering from the experience, and her partner cried during the entire interview, which she was present for. Since Carolina did not manage to reduce her identity goals, wanting to remain strong and in peak physical shape, she succumbed to the disease. She could not see perspectives for the future and did not want to continue chemotherapy treatments. If, on the one hand, she wanted to push the doctors into operating promptly, on the other hand she refused to question the effectivity of her own posture in the circumstances.

In Bruna’s case, her issue was linked to the fact that she had not managed to reduce her identity goals, holding onto the outrage she felt at losing her hair, and considering also the possible judgement of others, which added to her suffering. Her entrapment by these stigmas was hard to escape: *“(...) they have hair growing, but all of it ugly, all curly, all corkscrew! Black person’s hair! (...) I even asked one of the girls who was there with that frizzy hair: ‘do you have curly hair?’ She answered: ‘No, I had straight hair’”.* (Bruna) For her, straight hair ensured, besides femininity, that she belonged to the white population or ethnicity, and thinking that her hair might grow back curly deepened her horror for the disease. At one moment she mentioned that the experience of losing her hair was even worse than the possibility of death, stating that *“(...) my fear of dying is in second place”.* She considered her biggest hardship to be seen without hair, or for it to grow back curly. This rigid way of thinking, without the capacity for critical thought or for questioning, made her use every possible resource, daily and regardless of the temperature, so no one would see her bald. Her fixation on her old appearance, and especially her previously straight hair, made her succumb to her pain. In her words:

> Look, I’ll speak for myself, I had really straight hair, naturally, and for me it was the most beautiful thing in the world! I liked my hair even though I was a bit fat, I felt beautiful with it and all was well. Then I lost a bit of weight and things were even better! (...) But when I found out I was going to lose my hair, it was the worst thing in the world for me, I wasn’t afraid of dying, I was afraid of losing my hair. (...) The biggest difficulty I had was when my hair fell out … for me to go out in the street! Because I didn’t think about the disease, I just thought about my hair and what people would say about me, if they would criticize me in the street. (...) And now I think, what if it grows back ugly, frizzy? It’s very sad. (Bruna)

Carla’s experience brought pain associated to her losses, and among these losses was that of her daily job as a health care professional. Also, she realized she had grown a lot thinner with the disease, different from most of the women, who gained weight; she felt ugly without hair, and unrecognizable to herself, which she associated to psychological aspects. In her words:

> (...) our psychological side is smashed, for a start! It’s as if it wasn’t you there, this isn’t me, this isn’t Carla! There are days where I miss myself! *(tears)* You miss your job, what you were and what you did before, you miss your hair, for example, I even dream of hair! You become afraid, afraid of some things… *(twenty-second silence)* You’re afraid, for example, of not overcoming things, silly things! It seems like the fear of those who have cancer is bigger, like this, both in an aspect of pain, and the aspect of love, it feels like we’re more sentimental. Yes, that, we get more sentimental, for certain. (Carla)

Carla considered that she was more sentimental and associated that to the disease. As noted in item 2.5.2, she had many fears of not overcoming cancer, especially as she did not believe she had discovered the problem in time for a possible cure. Her duality can be comprehended upon noting that she did not reduce her identity goals while facing the disease. She maintained a protected identity, for example, thinking and acting as a health care professional. She did a lot of research about metastasis, and feared that the cancer could reach her brain, even though none of that had shown up in her exams or been mentioned by her doctor. She could not criticize her ideas, and this only deepened her sorrow. Another important point, which highlights this non-reduction of her identity goals, was the fact that she still felt strange about the body she was inhabiting. Even though the interview was carried out when Carla had already been through 15 chemotherapy sessions, six months after she began treatment, she still had not adjusted to her new body, affirming *"this isn't me"* and other statements such as *"I miss myself",* which reveal how she succumbed to the pain of the disintegration between self and body, triggered by becoming ill. Another issue that can be pointed out about Carla is her loneliness and isolation. She lived alone, but before the disease she went out daily for work, and sometimes to go dancing, a routine that changed with the disease.

2.6.4 The midway path: faith and religiosity as a possibility

The two women who had problems with their husbands while sick brought interesting experiences to this study, since both also talked repeatedly about God during their interviews. Aurora and Beatriz pointed to the figure or concept of God as their source of support, hope, and strength in the fight against cancer. In the words of Aurora, this is something she not only wanted to report, but to *"confirm"*:

> I confirm to you, that if I were not a woman of faith, I would have fallen, I would not have been able to stand it, because what he *(husband)* does to me, I could already be in a depression. But thank God, nothing, what God gave me was courage! God inspired me through that news story *(a program she saw on TV)* so that I don't need to feel guilty. And mainly, I told myself, that he *(husband)* is not worthy of deserving me. And I reaffirm, that's when his spell broke. I can't handle him anymore! I've never suffered as much in my life as I'm suffering now, not even when I lost my three siblings, who I helped raise. (Aurora)

Aurora, who had made up her mind about the divorce, suffered from her husband's behavior after becoming ill. As discussed previously, the couple's conflicts already existed, but before, she didn’t see divorce as a way to resolve the situation. In the excerpt above, we can see how she attributed her choices to God, going as far as to say that she received divine inspiration through a news story on faith and self-love, which helped her realize her husband was *“not worthy”* of remaining in her company. She compared the immensity of her suffering during her cancer ordeal with how she felt when she lost her siblings, concluding she was suffering more at the time of the interview, and claiming her strength came from God.

With similar conviction, Beatriz delegated to God the functions of confessor, mentor, and guide, setting her faith in place of professional help or even another person: *“(...) I was seen by a psychologist there* (at an NGO) *twice, but I decided to stop. Not because the psychologist wasn’t professional, she was great! But because I think we have to get closer to God, first, (...) only He has the answers.”.* (Beatriz) When she was immersed in conflict, both from the loss of hair and from the lack of support and caring from her husband, she complained to her doctor who sent her to a group (support network) and to a psychologist, who attended her at an NGO, without any cost. She didn’t want to frequent the group, but went to the psychologist; however, she gave up on psychotherapy, alleging that she would find her strength and answers in God. She explained more about this connection established with God when she felt sickest:

> I pray and speak to God, I don’t even speak to my husband... And this is why I left the psychologist, because I think that no one in this world can help me, except God. Because she, she listened... She listened, but she couldn’t do anything apart from listen! While God, he can help, he can change my sentence. So, it’s like this, now I’m in my cure process, thank God, I praise God, because now I have hope… I’m seeing my hair regrow and soon I’ll get my implants, and I’ll go back to being that person from before…*(laughter)* (Beatriz)

Brigite, a single and lonely woman, reported she had been Evangelical her whole life, having grown up in a religious family. Thus, she said she believed, as did her relatives, that diseases like cancer manifest in humans for two reasons: to make them go through trials and in order to reveal the power of God. With this conviction, she affirmed several times, in a calm and satisfied manner: *“Doctors, like us, are instruments in the hands of God. God gives them knowledge, and they bring us the cure.”* (Brigite)

Bianca, on the other hand, had plenty of support from her husband and family during treatment. What she brings to the discussion is the fact that she was not a religious person before getting sick. However, after going through a number of losses, mainly with regard to adverse reactions to chemotherapy, including loss of teeth, she sought out religion in order to *“find paths for the pain”.* After this, she became a believer, and considered that her life and that of her family had improved, as she had become *“more tolerant”* due to becoming *“a person of faith”*:

> (…) and another thing, I had no faith, none! I had faith in nothing, and I was cured by my faith! Because after the disease, I clung to God, I started being a practicing Catholic and today I know all the prayers… I had this experience when I was diagnosed and started looking for prayer groups, to find paths for the pain. And I fell in love! So, my cancer, today I see it with lightness, because it even taught me to like the people I thought were my enemies, and it was all through my intolerance! So, the disease, it ended up transforming me; today even my family as a whole is more united, mainly I believe because I’ve changed a lot, sometimes I’m a lot more tolerant, I’m a person of faith… Today I see it all with lightness. (Bianca)

It’s interesting to note that, among the participants from group C who were the poorest women in the study, faith, religiosity, or even God were not resources they turned to during the adversities they were dealing with. Even though some of them made sporadic mentions of faith, this was not identified as a “midway path” in the fight against the disease.

2.6.5 Redefining concepts of women and femininity

Something new emerged in the lives of the women in the study who managed to overcome their losses and adapt their identity goals to their new bodies, as well as those who found resources to deal with their suffering, such as faith. Most of these women found values that moved beyond their feminine bodies and their roles as wives and/or mothers, redefining their beliefs about being a woman.

Ana, Antônia, Aline, and Bianca stand out for their efforts to overcome their own adversities and to reach out to other women, seeking to help them prevail, too. Illness appears to have worked as a motivator for these women, who, after recognizing they had physical limitations that carried stigmas, adopted a behavior that exposed this socially. They took on mentoring attitudes, going beyond controlling themselves and their own issues to transmit this knowledge to others. In the words of Bianca: *“I loved being bald and I tell my friends who are in treatment: take that turban off for the love of God, you are beautiful without hair as well. I discovered vanity in myself when I lost my hair, I began using makeup and liking my face more.”* (Bianca) She abandoned her former regard for her hair and began to value her face, as well as her desire to communicate with others, going out in the streets bald to carry out her routine. She sought to promote a concept of beauty for women, even those with no hair: *“(...) you are beautiful without hair as well.”*

The other women who, like Bianca, also took on an above average social identity, acted in a similar manner. This included lecturing others on the importance of a healthy diet, and taking on a support network (ideas discussed in “Strengthening yourself, strengthening others”), all of which worked to move them in a direction of breaking free from labels or conducts that would have made their day-to-day with the disease more difficult.

Beatriz and Aurora, with the suffering that came from facing the disease, saw their ideas about marriage as a family institution fall apart. For them, this institution proved a failure, as both had to deal with the fury of their husbands when their sex life was interrupted by the illness of their “wives”. These women managed to envision for themselves a new life after divorce, breaking a paradigm they had trusted for religious reasons. They believed that they could somehow have better lives as divorced women then the ones they were leading, even if in the future.

Camila, a participant who, like the two previous women, adopted a contingent identity, discovered new values for existence in her children and in the unity that she felt within her family. She had been married and divorced twice and had four children: two older ones from the first marriage, one from the second marriage, and the fourth, still a child, born from what she called an *“adventure”*. Her life was dedicated to her job, and in her free time she liked to go to parties. Her two oldest children had gone to live with their father after the divorce, maintaining a restricted contact with her and her other children, until she became ill. Everything changed when she found out she had cancer and revealed this to her children, gaining their support not only in a financial manner, but also in terms of care and presence. In her words: *“(...) Because my values are now, for example, caring for my health, being well for myself and for my children. And letting them know I’m well. For me, the important thing now is to end my life with more love and more unity with my family.”* (Camila)

Brigite, Cláudia, and Cristina, women who adopted a protected identity, allowed a reduction in their identity goals to take place during their fight against the disease and, each in their own way, discovered new values for their concepts of women and femininity. Brigite, for example, was always a caretaker; she never married and helped raise her siblings, and then later her nieces and nephews. At the time she became ill, she was working as a nanny at a niece’s house, caring for her grandniece. The disease placed her in a position to be cared for, and this was new for her and meant allowing herself time to process the strangeness of the situation. In her words: *“Women who are used to working as nannies don’t like being coddled. But I was very sick. I felt horrible pains before surgery! So, I saw that the care of my nieces* (referring both to the adult and the child) *was to bring me food, give me comfort. (...)”*

(Brigite). Similarly, Cláudia allowed herself to be cared for by her children and grandchildren, people who she had previously taken care of in her roles as mother and grandmother. Additionally, she discovered that her health had a greater value than her desire for a thin body, reshaped by plastic surgery, as she stated in her interview: *“If I’m certain I’m cured, if my health returns to my body, I don’t even want to do plastic surgery anymore. What I want is to live to see the children of these two grandchildren who live here be born!”* (Cláudia)

Cristina found a new dream while fighting the disease. She wanted to finish treatment and go to college, so that in the near future she could stop being a homemaker. She wanted to get out of her house and work to help other women, just as she felt she had been helped by the group she frequented, one of the previously mentioned support networks.

This theme of support networks, discussed in “Strengthening yourself, strengthening others”, is taken up once more to finalize this thesis, since it points to a mechanism created among the women themselves. This mechanism serves to support those who are dealing with breast cancer, moving beyond institutionalized spaces. These networks can function as open spaces, where it is possible to discuss ideas, create new concepts, and question not only the doubts raised about the disease, but also the labels and stigmas that accompany it. These spaces, which are not always physical, may not be necessary for some women, who are capable (taking into consideration education levels and other socioeconomic indicators, as well as psychosocial aspects) on their own of breaking with pre-established concepts about women, health, and femininity. In addition, women may have other support networks that are not connected to the disease, but instead to different spaces of socialization. For the most part, however, support networks for patients with breast cancer, such as UNA, can be of great help to those sick women who, due to a variety of factors, are subjected to social constraints that limit the concept of what it is to be a women, especially when restricting this definition to the body, or to pre-determined roles or conducts.

PART II

3 PART II: RESEARCH IN GERMANY

As previously explained, the guidelines created by Charmaz (2009) clarify how data analysis should be carried out — line by line. Thus, the predominant codes in the interviews were gathered, contemplating all of the participant reports, while seeking to reach saturation in the processes of constant comparison. However, the same codes previously identified in the analysis of the Brazilian study were not always found at the same stage of the German study. In this manner, some categories had many similarities in terms of the two studied publics, while others were completely different.

For instance, the codes “health” and “physical exercise”, as well as “health” and “dietary care”, were completely interconnected in the reports of the German women, so the category “Defining the concept of health” was exclusive to this stage of the study. Another difference is that the codes “body” and “vanity” had no interaction for the majority of these participants, which once again set them apart; in this manner, the thesis based on the memorandums that contemplated the categories is also new.

It is important to point out that other work was also relevant in assisting the researcher in the analysis stages of this study, such as some that were developed using GT, as in the case of studies carried out by Brünner (2004) and Yingling (2018).

Brünner (2004) used GT methodology for a qualitative study that aimed at investigating the matter of the biographic influences of women’s lives on breast cancer treatment. The author, in her master’s degree thesis, worked with 10 German women who had lived through the disease and its therapy, and were free from treatment. All the women in the study described how the disease had changed their lives. The author only managed to obtain in-depth data with three of the women; however, with these, there was sufficient evidence to examine and compare them to each other. In Brünner’s study, in which she attempts a comparison with the findings of Corbin and Strauss, who also researched the subject of cancer, the author creates a curve for the disease’s course, based both on the women’s reports and on the medical view of the circumstances, involving treatments and other experiences. However, these individual curves identified by the author do not correspond to the cancer patients studied by Corbin and Strauss. Next, Brünner (2004) tackled the issue of the concept of the disease in an individual manner, for each of the women in her investigation groups; among these groups she managed to examine the personal attitudes and strategies used by the participants for confrontation, concluding that the importance given by breast cancer patients to their illness was directly related to their own life biographies. This particular research was useful for the present study, as it contributed toward the process of verifying the interviews carried out, with the intent of placing the women's speech in time: what they said about how they were or how they lived before cancer, and what they would be living at that present moment, as well as how they were acting, and, finally, what were their future expectations. With this, it was possible for the researcher, in conjunction with the other analyses, to recognize the identity choices the women might have adopted in the past, as well as how they positioned themselves at the time of the interview. Despite this, the intention was not to verify the biography of the participants, but the present moment, while they were forced to deal with illness.

3.1 An introduction of the socioeconomic issues of the women who participated in the German study

In Germany, as in Brazil, the study was carried out in partnership with a hospital that, among other treatments, offers health care to patients with different types of cancer. After this connection was set up with the institution, a nurse who specialized in studies and research, and who worked for the hospital, selected the interview participants according to the established criteria. The Kliniken Ostallgäu-Kaufbeuren is a large regional hospital, with a main campus located in the city of Kaufbeuren in Bavaria, as described in the Introduction (Methodology). The study participants lived in different parts of Bavaria, within the district of Ostallgäu, which contains 41 municipalities.

Initially, a total of 16 (sixteen) of the women approached by the hospital's nurse accepted being a part of the study and had their contact numbers shared with the researcher. However, after being contacted by phone by the researcher to set up a meeting, only 12 (twelve) of these women accepted a home visit for the interview. These 12 (twelve) women agreed to be interviewed individually and at their homes, following the same methodological steps used in Brazil. Each interview lasted on average 60 minutes. The other 4 (four) women contacted, who only wanted to speak over the phone, were excluded from the study despite having already answered the questions.

Table 3 introduces a general explanation of the socioeconomic data for the women who effectively took part in the German study. Their ages varied between 50 and 81 years. None of those interviewed had a university degree, although 6 (six) women — half of those in the study — had a German professional degree known as *Ausbildung*. This is a vocational and not academic training degree, carried out after high school and lasting between two and three years. Gomes (2018) explains that the *Ausbildung* is characterized by being directly linked to a grant-wage, where students work while learning and are paid for this. This type of schooling is in high demand in the country, absorbing a significant part of the labor force in different segments of the market and industry. Of the other half of participants, 4 (four) women had finished high school and 2 (two) only elementary school.

To maintain the privacy of the study participants, all names were changed, and the women were divided into three groups: K, L, and M, according to their fictional first names, as seen in Table 3. This method was used to facilitate the process of data analysis, taking into consideration the socioeconomic situation of each woman.

Table 3 – Socioeconomic Data of Women Participating in Research in Germany

Social Actor	Age	Marital States	Children	Education	Profession	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- Trade / 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

Source: prepared by the author using data from interviews with women participating in the research in Germany

According to Schacht (2019), Germany has one of the highest minimum wages in Europe, reaching a gross amount of around 1,500 Euros a month, since the hourly wage, which must be followed by law, costs employers at least 9.19 Euros. However, taxes and health insurance are costly, and the monthly liquid value that remains after deduction is around 1,100 Euros. The author also states that “In Germany, 60% of inhabitants receiving minimum wage are women.” (Schacht, 2019, p.1)

The average values for monthly family income, standardized for the study, were: 1000-2000 Euros, 2000-3000 Euros, and 4000 or more Euros. Thus, only one woman was classified within the social class with highest purchasing power, 7 (seven) women were in the intermediate group, and 4 (four) women were in the social class with lowest purchasing power. Group K has only Karen; in group L, with an intermediate income, were Larissa, Layla, Liane, Lisa, Loren, Louise, and Ludmilla. Group M, with a family income closer to minimum wage, were Marlene, Matilda, Melinda, and Mia.

In terms of family, all the women declared they were married, although one did not have a civil marriage as she was already a widower when she established a common-law union with her current partner. All the women in the study lived with their respective partners, without other relatives in the household. Even the women with children lived alone with their partners, as their children had already moved out. Only 3 (three) of the interviewees had no children, while the other 9 (nine) had between two and three children.

There was a variety of professions among them, with coincidentally 3 (three) estheticians, two of which were retired; all three had been self-employed and had trained for their profession with the *Ausbildung*. Of the others with professional training, one woman was a cook at a hotel, and 2 (two) others, now retired, had been buyers at large companies. Of the women with only high school education, there were 3 (three) production assistants (including an operator of heavy machinery) and one general services assistant. As for those with elementary schooling, one was a homemaker and currently a pensioner, and the other had retired as a seamstress. Therefore, out of the 12 (twelve) women interviewed, 5 (five) were retired at the time of the interview, one was a pensioner, and 6 (six) still worked. It should be noted that 4 (four) of the women — 30% of those interviewed — declared they were the main source of family income. However, three (3) women were no longer on sick leave at the time of the interview, and had already resumed their jobs.

3.2 Discovering breast cancer

The technique of using mammograms to track cancer is a practice adopted in many countries of Europe and the United States and used for over 20 years. (Bray et al., 2012; Breast Cancer Action, 2012) According to the authors, the different types of this disease can be identified early by means of screening, raising chances for a cure and for survival for the women with this diagnosis.

Regarding the tendency cited above, 6 (six) of the German women discovered their diagnosis due to periodical mammograms. 2 (two) women found out through exams they were carrying out for other issues, as one suffered from back pain, and the other had been through shoulder surgery, both having submitted to tests that led to a diagnosis of breast cancer. 4 (four) of the women noted changes in themselves and sought out medical attention. It is important to point out that all the women in this study declared they had already had at least one screening mammogram before.

The women who found out due to routine mammograms reported that they received a letter urging them to have the exam, a procedure they were used to taking part in every one or two years, depending on their age and family history of breast cancer. Only one said this was the second time doing the exam, having had the first at the age of 51, and the second at 53 years, when the disease was detected. According to these women — Larissa, Layla, Liane, Louise, Ludmilla, and Melinda (groups L and M) — between three days and a week after their mammogram they received a phone call from the clinic where the procedure took place, informing them that they should come in for more information. Most of them reported that, when they answered the phone, they thought of the possibility of cancer, because the clinic would only call after the exam if something was wrong. From Liane's report:

> In August last year I had done a mammogram, as I do every year, because you're invited here in Germany to do the mammogram, by the health insurance itself. There was nothing in my breast and I was entirely sure of that. The, the doctor from the current exam called me. "Goodness! What is this?!", I thought. So, I threw my hands up in fright, when she identified herself. But then I said: "yes, it's me and I'm well and not worried, because I had a mammogram last year, and it hasn't even been two months that I had an appointment with my gynecologist." So, she said there was something in my exam. "Ridiculous", I thought. And then she called me in to talk. When I got there, she soon took my hand. All my blood went from my body, I went cold, and I was shaking. (Liane)

However, despite their distress, they still hoped it wasn't cancer. The following excerpt reports the experience of one of the women in this situation, who became frightened upon first receiving the phone call, but afterward doubted the possibility of cancer, as she had regular mammograms and check-ups with her gynecologist. Her words relate to the idea that these conducts (mammography and consultation) can protect women against cancer. This is a misconception, since all these practices can do is anticipate a diagnosis. Liane stated she was frightened when she identified who was on the phone, however she thought it was all a mistake. When informed that something had been identified in her mammogram, she argued that she had done this exam before, and had been to the gynecologist, so she felt *"entirely sure"* and was *"not worried".* At that moment, the health care professional convinced her to go to the clinic and she did so. Her worry only surged at the doctor's reaction who, upon receiving her at the office, took her hand. It was at this instant that she identified the gravity of the situation, mentioning "*I went cold, and I was shaking*." A different case helps in understanding the experience of these women:

> I went to do a mammogram, because I got an invitation from my health insurance to do so. This was the second time in my life that I did this exam, and the first time I was 51. So that was two years ago. This time, a week after I did the exam, I got a phone call from Kempten (*name of city*), from the clinic where I did the exam. Because they don't give you the exam results, and they don't tell you anything when you do the exam, but you get a letter or a phone call if there is a problem. So, I immediately went there to find out what was wrong with my exam. And in two days they did a biopsy and told me that the result was nothing good. (Louise)

Like the other women who began their discovery through mammograms, and different from Liane, when Louise received the phone call from the clinic, she immediately went there to find out what was wrong, as she was alarmed from this moment on. Following this, she had a biopsy and received confirmation of a cancer diagnosis.

As for the experience of the two women who discovered the disease while doing exams for other health issues, both were surprised by the news of breast cancer. For Loren, the situation was complicated, as she had undergone surgery on her shoulder and had begun feeling intense pain over her entire thorax. Her cancer diagnosis appears to have been delayed, as she reports it took around three months after these intense pains appeared to identify the reason for them. Marlene, in turn, suffered greatly when the hypothesis of cancer was raised, refusing to believe it could be true. The experience of this woman was connected to the story of her daughter-in-law, a young person dealing with breast cancer who was gravely ill at the exact moment that Marlene received her diagnosis. In her words: *"Not long before me, my daughter-in-law was diagnosed with breast cancer. I was completely* *overwhelmed by this; I didn't know if she would survive! And then it was my turn, and I couldn't believe it. So, I was very shocked!"* (Marlene)

The women who discovered the disease themselves followed two distinct paths. Karen, Lisa, and Matilda identified nodules during a self-exam at home, and immediately sought medical attention, believing already that this could be cancer. Mia observed a secretion in her bra and initially thought it was dirt, maybe from her work in the garden; however, she saw this happen another time and noticed it came from her nipple. After this, she consulted her gynecologist, who requested the exams that showed a cancer diagnosis. In her words: *"First I saw a spot in my bra. It could have just been dirt, though that wasn't very likely. (...) Then I noticed a brown secretion coming from my right nipple, at the opening. So I went to the gynecologist, who sent me to do a mammogram."* (Mia)

3.2.1 Establishing a diagnosis

For a careful analysis of the data, initially transcribed in German and then translated into Portuguese, a line-by-line interpretation technique was used, as proposed by Charmaz (2009) in accordance with grounded theory. The aim was to locate the social place occupied by the study participants, as well as their positioning as social actors, and the influence this has on the discovery of a diagnosis. Additionally, the same process was used to examine the strategies adopted by the women in the study in order to deal with the disease and the treatments. As discussed in topic 3.1, three groups were formed to organize the study: group K, representing the highest socioeconomic level among the women; group L, representing the intermediate level; and group M, with the lowest socioeconomic conditions.

The experiences of diagnosis discovery point to differences in the processes these women went through, and which can be grouped into three specific situations. These, however, are not associated to the women's socioeconomic conditions. The following examples will help to contextualize some of the experiences, in order to clarify the phenomenon.

Of the women who discovered the disease through routine screening mammograms, 5 (five) were from group L and one from group M. They mentioned several times during the interviews that the situation was "*shocking/a shock*" — words that were used in all reports, without exception. The feelings of alarm began the moment they received the phone call (calling them into the clinic to talk about the exam), and for most lasted until they found out which treatments they would be submitted to. In all, this initial sense of shock and apprehension lasted between 7 (seven) and 21 (twenty-one) days, since all of them had to go through additional exams, followed by surgery. Only after the surgical removal and analysis of the tumor, could they know if they would need chemotherapy or radiotherapy. This is an important detail, because the fear of chemotherapy followed them throughout the process. Chemotherapy treatment was cited many times as their biggest fear, after they found out they might have cancer. In addition, they were worried about the stage of their cancer, and if it would be curable, as some said.

In this group, there were women who had gone through subsequent surgeries, as in the case of 2 (two) of them who had 3 (three) surgeries, and another 2 (two) who needed two surgical procedures within days. These subsequent surgeries took place after analysis of the tissue around the edges of the tumor (postoperative) revealed that the material removed was not within the safety parameters. Once this material pointed to contamination, a new surgical procedure was needed. In two cases, repeat surgery occurred as the sentinel lymph node, removed for analysis, was contaminated, demanding axillary lymph node dissection.

For Melinda, the alarm and sensation of shock were associated, besides to fear, to the speed of the process. After going to the clinic where she had her exam, she soon found herself heading into surgery: *"On Thursday I was doing the exams, and on Monday I was already in hospital. And, of course, shocked!* (She snapped her fingers and made a shocked face). *It was fast, I had no time to assimilate. Of course, the children* (adult daughters) *were also shocked.* (Melinda)

Next is Liane's report, already partially introduced in 3.2, a woman who at first instance, over the phone, did not believe in the hypothesis of cancer. For her, the disease was only perceived as a plausible reality after she met with the doctor. From first encountering the health professional until much later on, Liane reports finding herself in a "*state of shock*", uncapable of recognizing herself, manifesting behavior such as shaking and crying, feeling angry at the doctor, loss of control, and a sensation of mental block (what she calls a *"mind covered by a blanket"*). In her words:

> (...) so they sent me to the hospital the next day, to remove the sick tissue, or in other words, a perforation, as they called it. I wasn't myself anymore. I didn't know myself anymore, all I did was shake and cry. It was as if my mind was covered by a blanket. I was in a state of shock! It wasn't helping me, that I reacted that way. And that's when I hated her *(the doctor).* I thought it was all her being crazy, that I didn't have it. And I ended up pressuring myself a lot... So, in a week the results arrived, and the histological findings unfortunately confirmed breast cancer. (Liane)

For Layla, it was a situation of insecurity and of shock, as she went through three surgeries before submitting to the prescribed treatments. According to her, the surgeon was removing parts that were too small, which led her to believe she would not be free from the tumor. This made her irritated with the doctors, on the day of the last surgery, as she reveals in this excerpt: *"(...) I had to go back again and have a third surgery! And so I said: 'You should do the surgery getting a larger area, I don't care about my breast, because what you're doing to me is hard. I feel insecure and irritated!'"* (Layla) However, after this moment she reports receiving information that helped her reestablish a sense of calm and develop trust in the process: "(...) *But then a doctor told me that the tumor wasn't encapsulated, but instead had ramifications that grew in all directions, making surgery difficult. So, what could I do? Give myself over to them with trust!"* (Layla)

An unusual situation that, incidentally, was named an *"accident"* and *"accidental"* by the 2 (two) women who lived through this, was the fact that they had not noted any nodules on their breasts, nor did they discover the disease as most of the others did, by means of routine mammograms. In Loren's case, she stated that she already had "cysts" on her breasts dating several years back, and due to paid frequent visits to the gynecologist, having been through various exams that pointed to the cysts being benign. However, during the postoperative period for shoulder surgery, she began feeling great pain, without knowing for sure where this pain was coming from — shoulder or thorax. As she had to use a cushioning device during her recovery, avoiding moving her arm, which was left to hang across her thoracic region, she spent around six weeks without being able to observe her breast. When she no longer needed the cushion, she soon noticed that her breast, on the side corresponding to the operated shoulder, was *"deformed".* At that moment, she imagined that the pain could be related to the mammary "cysts" she already had, and that there must be some problem besides the shoulder. The following excerpt shows how she discovered her cancer — the longest time diagnosis period among all those interviewed:

> I immediately called my gynecologist, who was accompanying the cysts, because I wanted to describe that my breast was deformed. (...) But I found out he had retired. So, it was a wait between the six weeks of pain *(with the cushion at her shoulder)* and then three months in all, until I found out what I had. Because I thought: "well, so I'll wait until the new doctor is there after the new year". (...) And I only managed the first meeting in the beginning of March. So I was obliged to wait. Then this new doctor examined me and then he saw that my breast was deformed. And he immediately did an ultrasound and was of the opinion that it was a complicated cyst, that it must have been there for two years, and that if it were a cancer, it would have been discovered before, not like this, accidentally. He sent me to hospital. (...) Then at the biopsy at the hospital it was confirmed to be a very aggressive cancer. (Loren)

Loren’s case stands out because it could be that the cyst, already noted some years previously, and monitored both by mammograms and by ultrasound, had become cancerous; or yet, that this cyst was later confirmed as cancer. This was not clear to her, and there were no comments on this in her *Nachsogerkalendar*, so it will remain unexplained. However, her report showed a certain amount of passivity, as there was a long and painful wait until she managed an appointment with a gynecologist. She stated she was *“obliged to wait”.* But she also mentioned she wanted to wait for a new doctor to arrive at the clinic in place of her old one. This took around three months. When associated with the facts, we can see a certain initial lack of preoccupation on her behalf, or even a lack of knowledge, about a possible cancer diagnosis. Additionally, it appears that she had an excessive amount of trust for her former doctor, since she insisted on being attended at the same clinic.

The experience of Marlene was similar to that of Loren, in that she was not actively seeking a cancer diagnosis, but instead a solution to back pain issues. However, her case also had an unusual component: it was her family doctor who suggested she do a mammogram in order to clarify a footnote comment (left by a radiologist) on her spinal exams. She was convinced she was only doing a mammogram to satisfy her doctor, who was in her opinion a friendly and trustworthy person. She was sure there was nothing important happening in her breast, as she couldn’t feel any nodules, and her pain was perceived as originating in her back. The following excerpt brings important observations:

> I discovered the cancer by accident. I went to the doctor because of my spine, I had back pain. He sent me for a computerized tomography, and in the result, the doctor wrote at the end, really small, an observation, "small spot on left breast", but "discreet" he noted. So, my family doctor looked at it in astonishment and said: "Mrs X, you haven’t had a mammogram in a long time, do a mammogram!" I thought that was silly, I was sure it was just back pain. But then, he was so kind. (...) And that’s how it all started, as I say, accidentally. (...) (Marlene)

The 4 (four) women who noted something in their breasts themselves, and sought immediate medical attention, following the tendency of the group who discovered their chance of disease by means of mammography, were apprehensive at the thought of something in their breasts that had not been there before. However, their fears began the moment they found alterations in their bodies (the lump/nodule, or the secretion), and lasted longer, compared to the others. They had to wait for an appointment with a gynecologist to only then be referred to a mammogram and, after, to other procedures. An exception in waiting times was Karen who, due to having private health insurance, was seen by a doctor just one day after feeling a lump in her breast. And even this delay was because she found the nodule on a

Sunday, when private clinics were closed, and she knew it would not be a case for emergency services, but for a gynecologist or mastologist:

> I was sitting there watching television, I put my hand here *(showing her breast with her hand*), and then I noticed there was something solid, a hard spot. It moved a little when I touched it, but it was clearly a solid lump. And it was a Sunday, so I thought: 'what do I do?' (...) So I decided: That's it! I need to act. So, next day, a Monday, I was at the appointment with my gynecologist and he said: "Mammogram, immediately ". So, I went immediately to the hospital. And the next day I went back to the gynecologist with the exam done, and he confirmed it was breast cancer. (Karen)

Lisa, Matilda, and Mia did not have the same luck as Karen, either because they had state health insurance, or due to busy schedules at their doctor's clinics, and they all had to wait a few days for an appointment. Even so, none of them waited more than 10 (ten) days to see a gynecologist. Once a doctor saw the urgency of their case, all exams were set up and carried out immediately, as in Karen's situation. According to Lisa: *"I noticed it on my own. I felt the nodule last year on carnival Tuesday, after my bath. So, I immediately went to call the gynecologist. I managed an appointment for the next week. (...)After that it was all frenetically fast."*

Matilda found more than one nodule in her breast, while taking a break from her house chores — her husband had been abed for three years, which left her overwhelmed with work: *"I was frightened at the nodules, and I wasn't sure when they had emerged or what they were. (...) So I went to the gynecologist. He did an ultrasound and didn't like it either. (...) So, with the results, he explained it was cancer."* (Matilda)

In the case of Mia, the woman who had noticed a secretion, she had done a routine screening mammogram not long before, *"only five months before"*, and the exam had shown nothing. Thus, when she approached a gynecologist, she underwent other procedures: *"(...) they did a smear test for biopsy in Augsburg, and that's when they noted there were malignant cells in the breast and something had to be done immediately, including exams to see if they were in other parts."* (Mia)

To finalize this topic, we return to Karen, who had stopped doing periodic mammograms when she turned 70 (seventy) years of age. At the time she discovered the disease, at the age of 80 (eighty), Karen didn't think older women could have breast cancer. Even so, she had always carefully observed her body, because, she explained, she had been an esthetician for many years. She had leant to observe spots, blemishes, nodules, and anything else, not just on her clients' bodies, but on her own. She explained in detail what happened to her, a misconception she had believed in for around 10 years and which was shared by her friend group (all approximately the same age), who had also stopped doing mammograms during that period. In her words:

> I have to tell you honestly, I never thought this would happen at this age. This made a profound impact in my mind. I have a private health insurance, which is really a little different. But my friend, who has a state health insurance, always did her mammograms through her insurance. And so, when she completed 70 years, her health insurance didn't call her for any more exams and didn't pay for it when her doctor asked for one. So, she told me this at a café, where we would meet to talk every week. And we thought together, five women, all of us friends our whole lives, that probably you don't get breast cancer any more at this age. We were all of the same opinion. (Karen)

Karen was disappointed in herself for believing that age would protect her from breast cancer. As a consequence of the new reality she was facing, she started researching among acquaintances from the medical area what was wrong with the health insurance system that stopped paying for her friend's mammograms, and which ended up indirectly leading her and her friends to stop periodic screening. She found an answer, which she passed onto her friends: *"Dr. X, who is also an oncologist, has no doubt that the exam is very expensive for the insurance company, as there are a lot of older women here. Age does not protect against breast cancer, the women and the health insurance have to know this."* (Karen)

3.2.2 Sharing or hiding the news and identifying a support network

All the women interviewed, without exception, shared their diagnosis first with their husbands. Simultaneously, for 10 (ten) of them, their husband was identified as their biggest source of help and support during treatment. However, 2 (two) women could not count on help from their husbands, as their spouses were not able to support them in daily activities, let alone accompany them to treatments. Both were living through a similar situation; Matilda's husband had suffered a Cerebrovascular Accident (CVA) a few years before and, consequently, had lost motor functions. He could not walk or move his arms and depended on her for everything, even eating. Mia's husband, who had also suffered a CVA a year before the interview, had severe motor limitations, and could not leave the house. However, Mia did not need to feed him, as he still had a certain independence of movement, being capable of bathing and feeding himself.

An important observation that came to light in the study was the lack of support from social networks, especially from the extended families of some of the German women. They frequently spoke about only being able to count on their spouses, and sometimes children (including sons- and daughters-in-law), to help with cleaning the house, shopping, and other daily tasks. None of the interviews mention other relatives, friends, or even neighbors visiting in order to help in some manner when they had the disease. This demanded an effort to understand the circumstances that lead to this sort of social isolation, since all the women lived in small country towns, surrounded by people.

From the moment the diagnosis was received until a support network was identified, the reports revealed that most of these women felt ashamed for having cancer. In general, with few exceptions, they tried to hide the fact that they were sick from people, whether work colleagues, relatives, or neighbors. Their main attitudes and justifications can be grouped in an attempt to comprehend this phenomenon.

Mrs. Karen, the oldest among those interviewed, had no children but many friends. Besides her husband, her only relative was a sister, 15 years younger, who she said she got on well with. She considered the fact that they lived far away from each other as the only deterrent to a constant interaction. Karen managed to hide the disease from her friends for almost 2 (two) months, however, when the end-of-year festivities arrived, her friends suspected her "problem" and sought her out. From this moment on, she shared what she was going through, as she felt the shame of lying was worse than the shame of having the disease. When her radiotherapy sessions ended, she went back to her weekly encounters with her friends. The intensity of her experience is clear in this excerpt:

> The fact happened two months before Christmas and, after that, of course I wasn't there for my friend group's Christmas celebrations. So, they thought, "if X hasn't been meeting us, X must be sick. Yes, if she's sick, what could be wrong with her? What is her problem? Let's go to her." I can't say that I'd never been sick before, because at a certain age you are always sick. But now I had taken a long time to return. So that was how it went. As the group noticed I was missing, I had to admit I was sick. But telling, talking about it, I had only really told my sister until then. My partner was already with me. Anyway, my circle of friends heard after Christmas. (Karen)

Karen, at the time of the interview, was still trying to deal with the reactions of her friends to her new state of health since, according to her, her friends started treating her with a certain *"pity",* unlike her sister's reaction, or her partner's: "(...) *It was something different, they started pitying me. My sister, though, was more positive and said: 'You can deal with this, it's not that bad.' My partner is a dentist, and so he reacted in a different manner in any case, as doctors don't react like normal people."* (Karen)

Comparing the reports of the other women, it was possible to observe that the higher the education level, the greater the effort to hide the diagnosis. And, simultaneously, the women with higher education levels were also the ones with more social contact networks previous to becoming ill, so hiding their sickness demanded more efforts from them.

For Larissa, Layla, Liane, Lisa, and Mia, whose educational level was the *Ausbildung*, not revealing the disease meant not placing themselves in a situation where they might be judged or subjugated socially; this also preserved them from general opinions on breast cancer and on the possible effects of treatments. They pointed out that they thought other people's opinions about the disease might frighten them more, and even bring inappropriate anticipation regarding what they would suffer during treatment.

Layla and Mia, both women without children, had an immediate family that was restricted to them and their husbands. Both had siblings who they considered to be on an equal standing with people in other social groups. Both of their reports mention groups of friends and acquaintances, people with whom they had an intense social life previously, either professionally or for leisure activities. However, neither of these women sought out their friends to share what had happened, although, just as with Karen, some of these people found out through going up to them and asking. Mia's story sheds some light on the position that these women adopted:

> I don't say anything to my friends. With them *(two who have already had breast cancer)* then, I say even less than what I sometimes say to the others, which has only been happening over the phone. And I didn't tell or ask them particularly anything, because I think it's different for everyone who treats this disease. If they told me, for example, that I would have this, this, and this complaint, then I would get scared. And you don't necessarily need to pass that along. (...) My few friends who found out, somehow, they encouraged me. But I believe it was because the two in our circle of contacts are well. This happened to them some years ago. And so, I think it will be like that with me as well. When I get better, I'll go back to meeting them. Therefore, I don't have to keep talking about it. (Mia)

Lisa and Liane, who also tried to hide the disease from friends, relatives, and acquaintances, had interesting behaviors in this sense, noted by the researcher from the very first contact, over the phone. They asked the researcher emphatically not to, during the home visit, ask anyone for directions, and not to mention cancer, as their neighbors didn't know and could not know that they were ill. This fear stood out, since there was no reason to be asking for the women by name on the street, let alone mentioning to a third party the reason for being there.

Lisa, who had not told anyone outside of her immediate family circle of husband and married children, complained of her three sons, saying that the fact they were men had never been as bad as then, when she got sick. She considered that they didn’t help her or support her during her sickness because they were being men. Thus, she suffered greatly attempting to take care of herself, of her home, and also of her father´s house and some things for her mother-in-law, since both were elderly and ill. She cried during the entire interview, making it clear that she was unsupported and overwhelmed, as can be seen in the following excerpt:

> My children didn’t want to believe in it *(cancer)*. They blocked it out somehow. They only said: "Mother, you’ll get better". It’s like this, because they’re guys, they’re boys! They don’t know how to help. Girls take you by the hand and do things differently, they do what they need to do. My boys have taken me by the hand before; like when I lost my job. But with this, with cancer, it was different. They didn’t know how to help! I had to take care of my elderly father, of my mother-in-law who is their grandmother, and do everything alone, because my husband works a lot. (Lisa)

In Lisa’s report, we can note how she revalidated the idea that there are social roles for men, and others for women, as her sons at the time of the disease did not help her — she made it clear that they did not show up to care for her, either in terms of her treatments or with domestic chores. She considered this conduct to be an attitude of “*boys”* (referring to her children’s gender). In addition, she went on to talk about how they helped her when she lost her job, explaining the type of assistance they gave her: “*The three are good boys, they didn’t let us go through financial difficulties when I lost my job before the disease. They got together and gave me an allowance every month, so their father and I could maintain our income.*” (Lisa) Thus, when she accepts and incorporates in her discourse this separation of gender roles, she most likely transmits this idea to her sons. When historian Joan Scott (1989) introduced the idea of “Gender: a useful category of historical analysis”, from a scientific approach, she was referring to the impossibility of looking at social constructions without paying close attention to the relational dimension of the masculine and the feminine, as well as everything that can be found between those two points.

Different from Lisa, Liane and Larissa had plenty of support from their children, who helped during exams and treatments, and were present and dedicated toward their mothers, caring for their different needs. But, just like Lisa, Liane feared letting others besides her immediate family know of the disease: *“In truth, if you have cancer, you’re labelled as sick and I don’t want that! I have cancer, fine, but I have it now. I feel healthy and I want to maintain my privacy. I’m in treatment. I don’t want them thinking: ‘Oh, poor thing, you’re not* *going to live.'"* (Liane) For these two women, their children were a big source of assistance and trust, not just in terms of daily care, but for emotional support while they suffered from the disease. According to Larissa: *"My children guided me regarding care and bandaging. They helped with my arm and helped me with everything, even with resting, so I could go back to being able to move. They were very positive. And I can honestly say that this helped a lot."* (Larissa)

Among those with high school education, Loren, Louise, and Ludmilla worried about hiding their diagnosis and not letting others realize they were ill. Different from those with an *Ausbildung* education, it was not possible to identify anything in their reports that pointed to a direct association between the possible acknowledgement of others regarding their disease, and consequent labeling or stigma. The key issue for these women was not calling attention to themselves, not making a "*scene*", not being the reason for an outsider's gaze:

> The wig, something that in truth I wished I had spared myself from, I used it a few times. At first, I used hats or knitted beanies, because I didn't want the entire neighborhood to know. I didn't want to be the bald 'scene' of the street. And then, a neighbor asked me once, why I was always wearing that hat under the hot sun. It was the height of summer, and I really was hot! As I was always sweating a lot, I had to tell her the reason. So, I explained that I was sick, and that the hat was to spare people, like her children, who wouldn't understand why I was suddenly bald! After that day, I bought a wig and used it without fail. (Loren)

Loren was one of the few women to go through chemotherapy, which didn't help her attempts to hide her diagnosis. As she mentioned, the hat she was using to cover her bald head called her neighbor's attention, leading her to buy a wig in order not to raise any more questions. For Loren, use of a wig was a strategy used to protect herself from social exposure, not to complement her appearance.

Louise and Ludmilla were more worried about preserving themselves in their work environment. Besides levels of schooling, they also had in common the fact they were both foreigners. Although they had lived in Germany 28 (twenty-eight) and 30 (thirty) years, they married in their countries of origin and moved to the country of the study with their husbands. Louise was from Poland, while Ludmilla came from Italy, both leaving their birth countries behind in their youth in hopes of finding a better life in Germany. In this manner, they built their nuclear families with their spouses, maintaining a physical distance from siblings, parents, or friends, who remained in their countries of origin. They were emphatic in stating that their children and their sons/daughters-in-law where the people who, after their husbands, supported them in everything. These women reported that their circles of acquaintances were restricted, and their biggest worry was not allowing their work colleagues to find out about the disease. In their words, they didn't want to become the *"center of attention"* in their work environment upon returning from medical leave. It is interesting to note that both were already back at work at the time of the interview, and stated they were feeling good about the fact that no one had approached them to ask or speak about their cancer. This excerpt from Louise's interview is representative:

> I was obliged to go back to work earlier than I imagined, as my rehabilitation was denied. And it's not easy to sweep, to use a mop all day long, because I still have pains in my breast and my arm. But at least no one's come to ask me anything. I think I prefer it like this, living without rehabilitation *(a type of health service)*. One woman there went to rehabilitation once, and everyone found out she had cancer. When she returned, she was imploded with questions and became the center of attention at FFF *(fictitious name for the company).* I don't want that for myself. I like living this way in Germany, anonymously. (Louise)

An exception among the women who had completed high school was Marlene. She was the only one who told several people about her illness, which set her apart from the other women with the same level of education. She used chemotherapy as her justification for telling all those around her: *"There's no hiding this! At first only my husband and children knew, but after chemotherapy I told my relatives and my friends. Also, some of the neighbors! Because you can't hide everything, especially hair loss."* (Marlene)

Finally, there are the two women with lowest education levels, Matilda and Melinda. Both seemed indifferent as to others knowing or not that they were ill. They said they had only told their husbands and children, but believed that their neighbors, friends, and other relatives also knew they were sick. According to them, the fact that they lived in villages meant that everyone knew of each other's lives, without this making any effective difference for them.

Melinda stated that, in her day-to-day, she only had her husband helping in household chores, as well accompanying her to treatments. She also shared that they often went together to pray at religious groups, to help her reestablish her health. However, she said they never spoke openly of the disease at these groups, as they felt the subject was taboo within that context. She talked about her neighbor, a young woman with two small boys, who also had breast cancer, but in an advanced stage, as Melinda would observe the woman's convalescence. However, the neighbor did not allow her to approach, reprimanding her for her attempts and making it clear she did not want contact, even though they had the same disease.

Matilda, the woman whose husband was gravely ill, appeared at the interview to be physically debilitated and very depressed. Her words point to the lack of support networks in her life — an elderly woman trying to care for herself and for another elderly person: *"Because he was already sick* (pointing to her husband, in bed) *and then I got sick too. What else is left to do but go through with it? — I thought, and I believe that's what other people think! If they think that, why don't they show up to help. (...)"* (Matilda). Right after this was voiced, she was asked about her children, and if they also acted in this manner: *"don't they come to help?".* She answered in just a few words, saying that they had their own lives and their own problems. Then she began to cry and, while attempting to hide her tears, spoke between sobs and gasps: *"(...) No, I have no one to expect help from! I had to go alone by taxi to all the chemotherapies and radiotherapies. So, I went in those taxis that are paid by the health insurance to take people to chemotherapy and radiation."* (Matilda)

The home visit to Matilda was a difficult moment for the researcher. It was evident that this woman was all alone, and that she needed immediate help. However, it was also clear that, somehow, those who should have been supporting her — her daughter, her son, and their respective spouses and adult children — were neglecting this elderly couple. The fragility of both was exposed, and they were no longer in any position to be living alone. The field journal entry registered that there was a strong bad smell in the house and dirt everywhere. The husband was on a gurney in the living room and whimpered the entire time, calling for his wife. She would react by answering: *"I'm coming!"*, looking in his direction. When she turned back to the researcher, she would say: "*Don't listen, he's been shouting all day long for three years, he isn't feeling anything, it's just the suffering of being in bed."* (Matilda)

It is worth noting that the issues that Matilda was dealing with, and Mia too, in a less drastic manner, are not a natural family phenomenon, but instead are associated to an interventionist State and all the welfare benefits that this system entails. This can be clarified through the work of Teixeira (2013), whose discourse on the theory of modernization, from a structural-functionalist perspective, reveals that the reduction of family roles has as a consequence the loss of the immediate protection of its members, especially children and the elderly. The author makes it clear that, when the State, in its efforts to ensure capitalism, overrules family life and the support of different informal providers of well-being, such as the neighborhood and the community, taking over — completely or partially — the functions of these groups, a vacuum is created inside the family. However, specialized public institutions cannot simply step into this vacuum established within family institutions. Because even though the State supplies demands such as childcare, educational training, pension, retirement, and health insurance, for instance, it cannot fulfil those roles that are intrinsic to the family sphere. Among these are care with hygiene, feeding, and matters of affection.

3.3 Dealing with treatment

Continuing the analysis, it is necessary to discuss the treatments to which the women were being subjected, and that are summarized in Table 4. The table also cites the type of health insurance used by each woman, and that was subsidizing their treatments. Of the 12 (twelve) study participants, 11 (eleven) were being treated by means of State health insurance, with only one woman using private health insurance. Time of diagnosis lasted anything between 7 and 18 months, and none of the women had concluded their prescribed treatment at the time of the interview.

Table 4 - Diagnosis and Treatment of German Women

Social Actor	Health Coverage	Cancer type	Diagnosis Time in months	Surgical Treatment	Chemotherapy treatment	Treatment Radiotherapy and Medicines
Karen	Private Health Insurance	Mammary Carcinoma Not Specified	7	Quadrantectomy with axillary dissection right	-	24 sessions + Tamoxifen
Larissa	State Health Insurance	Lobular Carcinoma	10	Quadrantectomy of the right breast with sentinel lymph node research	-	16 sessions
Layla	State Health Insurance	Mammary Carcinoma Invasive	11	Quadrantectomy of the right breast with sentinel lymph node research	-	26 sessions + Letrozol + Exemestano
Liane	State Health Insurance	Invasive Ductal Carcinoma	9	Quadrantectomy of the right breast with sentinel lymph node research	-	16 sessions + Letrozol
Lisa	State Health Insurance	Lobular Carcinoma Invader Lymph Node Metastases	18	Quadrantectomy with axillary dissection left	-	28 sessions + Tamoxifen +Antidepressant + Anxiolytic + sleep inductor

Social Actor	Health Coverage	Cancer type	Diagnosis Time in months	Surgical Treatment	Chemotherapy treatment	Treatment Radiotherapy and Medicines
Loren	State Health Insurance	Lobular Carcinoma Invader Lymph Node Metastases	15	Quadrantectomy with axillary dissection left	15 sessions	24 sessions
Louise	State Health Insurance	Mammary Carcinoma Not Specified	7	Quadrantectomy with axillary dissection right	-	24 sessions
Ludmilla	State Health Insurance	Lobular Carcinoma	18	Quadrantectomy of the left breast with sentinel lymph node research	-	28 sessions + Herceptin®
Marlene	State Health Insurance	Lobular Carcinoma Invader Lymph Node Metastases	16	Left mastectomy with axillary dissection - Without reconstruction	16 sessions	28 sessions + Letrozol + Antidepressant + sleep inductor
Matilda	State Health Insurance	Lobular Carcinoma Invader Lymph Node Metastases	9	Quadrantectomy with axillary dissection left	16 sessions	34 sessions + Letrozol
Melinda	State Health Insurance	Lobular Carcinoma	15	Quadrantectomy of the left breast with sentinel lymph node research	-	16 sessions + Tamoxifeno
Mia	State Health Insurance	Invasive Ductal Carcinoma Multifocus	10	Quadrantectomy with axillary dissection right	-	28 sessions + Letrozol

Source: prepared by the author using data from Nachsorgekalendar, and interviews with women participating in the research in Germany

All the women had already been through surgery to remove the tumors — considered the definitive treatment for breast cancer. The prevalent type of surgery was a quadrantectomy, with 11 (eleven) participants undergoing this procedure. Only one woman, Marlene, had a radical mastectomy.

For 4 (four) women, chemotherapy was also prescribed. However, one refused this type of treatment, which will be discussed later. The 3 (three) women who went through chemotherapy were Loren, Marlene, and Matilda. Loren was the only woman to use chemotherapy as a neoadjuvant treatment, in other words, before the definitive surgical procedure. Finally, all the women went through radiotherapy, with a total number of sessions varying between 16 and 34, most of which were prescribed as adjuvant treatment, administered after the surgical procedure. Hormonal medication was prescribed for 9 (nine) women, and this included Tamoxifen, Letrozole, and Herceptin®.

3.3.1 A sigh of relief: "freedom" from chemotherapy

The biggest fear observed among the women, upon receiving a confirmation of breast cancer, was that they would be prescribed chemotherapy. The first reason for this fear could be identified as an association of sorts made between chemotherapy and the possible severity (advanced stage) of the cancer. In this manner, receiving chemotherapy treatment for cancer would mean that the disease could be more serious and threatening, with a lower chance of a cure. Conversely, not being prescribed chemotherapy would indicate, according to their assumptions, that the cancer was less serious or at an initial stage. The second motive to fear this treatment was connected to the observation of the experience of others, as some of the women stated they had seen or known someone who had been through chemotherapy and become very frail, or even died because of it. Additionally, many of them had read about the subject as soon as they found out they had breast cancer and had discovered the extent to which chemotherapy could cause the organism's immunodepression.

Among the participants, 4 (four) women, equivalent to a third of those interviewed, received medical recommendations for chemotherapy treatments: Layla, Loren, Marlene, and Matilda. Loren reported that her tumor was reduced from 5 cm to 0.6 cm with chemotherapy, which indicates that, in this case, the treatment was crucial. The experiences with treatment, however, will be described in a subsequent topic. Layla, on the other hand, refused the treatment, and had a different experience from the others. In her words, we can note some of the reasons for her decision:

> (...) Of course, I arrived full of drugs from the hospital *(after her final surgery)*, and maybe I don't remember everything, but I know I was very sick there. But that — chemotherapy, didn't knock me off my track. I got rid of it myself! For the love of God! I think it's something that everyone has to decide for themselves. My husband, of course, I also have my mother who is 90, if one day they need it, they have to decide for themselves. However, I didn't accept that treatment. I am 67 years old and this is the only time I will be 67! I believe that I really don't have much time here, but I am content that I chose this path. I felt it! So, I don't know about you, but what I've lived here, as an esthetician, and having among my clients many with cancer... And when I would see someone, one of them who had been through chemotherapy, that person either would die very quickly or be very ill, completely out of it, and for at least 2 years. (Layla)

Layla’s professional and personal experiences had brought the opportunity to interact directly with several people who had been through chemotherapy. Thus, she feared that her life would be taken over by the treatment, as she had observed with some of her clients at the esthetic clinic. When she stated: *“(...) chemotherapy, didn’t knock me off my track”*, it’s hard to understand at first what she means by it. However, at the end of this excerpt we find*: “(...) that person either would die very quickly or be very ill, completely out of it”*, where she explained how she perceived her clients who had been through chemotherapy. This helps clarify the sense she gave to what she called *track*, or the path of her life. Leaving her path, or being thrown off-track, would be to shorten her life span, dying too quickly, or living without control or self-awareness, what she called *“completely out of it”*. Layla saw this power to take someone away from their path or track in chemotherapy. This helps us to understand why she emphasized her age, affirming she will only be that age once, as if wanting to live that moment intensely. And it is relevant to note that she added to her report the notion that maybe she had not that much longer to live, however, that she was satisfied she had opted out of the treatment. On the other hand, she made it clear that each person must decide for themselves whether or not to undergo chemotherapy.

This woman’s decision was to take a stand against medical prescription, which brought cascading issues both with her doctors and her health insurance. Initially, when she communicated to her doctors that she did not want chemotherapy, she was advised to seek out another medical team and hospital, and to look into the chances of undergoing different treatments. She remained firm in her decision and argued with the doctors from the hospital team in order to be able to remain with them and yet use different approaches that did not include chemotherapy. Among a series of impasses, which she described in detail during the interview, was the fact that her health insurance had denied payment of radiotherapy, notifying her that the treatments were linked and dependent on each other. She ended up having to buy many of the medications prescribed herself, due to the issue with her health insurance and the impossibility of waiting for an outcome due to pain, as well as the risk of the disease advancing during this period in which her insurance refused to cover her treatment. At last, she managed authorization from her health insurance, through the intervention of her doctors (hospital team), for payment of her radiotherapy. She was disappointed by this situation since, after spending most of her life contributing towards her health insurance, she found herself helpless when she needed care: *“I have 51 years of contribution in this system, as I’ve been paying everything since I was 14 years old, I’ve been* *contributing almost my entire life. I found it strange that the Health and Welfare Insurance, when I got sick, did not give me full support."* (Layla)

Different from Layla, chemotherapy was not prescribed for 8 (eight) of the participants. This fact brought them relief, as well as the hope of reaching a less painful cure for the disease. It is worth pointing out that, in the reports of 4 (four) different woman, they mention doctors congratulating or commending them for not needing a chemotherapeutic prescription. Two excerpts confirm this experience: *"He* (the doctor) *came down the hallway and said: 'Mrs. X, you can open a bottle of wine or champagne today! Because for you, it's like winning the lottery. You don't need chemotherapy.' That was really great, I also got excited."* (Melinda) Like the doctor, Melinda affirmed she also felt motivated by not needing that particular treatment, as *"I thought that if I went through that at the age that I'm at, I might nor resist, and see my body fail. So, I was encouraged."* (Melinda) According to Louise's report, the situation appeared to have been similar: *"One of them* (doctors) *was the one who said: 'Congratulations, you will only need radiotherapy, as the exams of the tissue taken in your surgery were not so bad.' But I was already thinking they would be much worse, so this immediately made me feel better!"* (Louise)

Liane clarified the tension she felt while awaiting her biopsy results, which would indicate which treatments her case required. She was aware that a medical team would be meeting, as per usual, to define what to prescribe. She could not control her anxiety and fear, and decided that if she needed chemotherapy, she would avoid treatment and no longer return to the hospital. At the appointment, she was accompanied by her family (husband and 3 children), and when they heard that chemotherapy would not be necessary in her case, they all made the *"sign of the cross",* a gesture of praise and thanks to God, as seen in the following excerpt:

> It's because there are around 12 doctors from different hospitals, they meet in there and discuss each case, so they can decide which treatments should take place. (...) And so it came to the appointment, the moment where they would tell me something. I left here shaking. 'Chemo?', I thought, 'I'm not going to pack, I'm not even going to leave the house, no one is going to see me there anymore, if I need that!' Yes, I can recognize that I was shocked. (...) So all the family went, and we were in a strong state of emotion. My children were around me daily, and so was my husband. And there, when we found out it would be just radiotherapy, we all made the sign of the cross. It was a grace we received from God, so we gave thanks. (Liane)

The reactions to receiving the news that they would not require chemotherapeutic treatment were similar. For Lisa, for example, *"(...) That's when they told me, two or three* *days after I left the hospital, that I would not need chemotherapy, only radiotherapy! And I thanked God for that! It was a release".* Only Larissa and Karen did not mention God in association to this victory. However, they were also relieved by it. In Larissa's words: *"(...) And then I received a recommendation for 16 radiotherapies. And it has all gone well until now. I just have the normal controls, that I still have to do. But nothing more than that, no chemotherapy! No pills, no medication. So, I feel positive."* (Larissa)

For Ludmilla, thinking about chemotherapy reminded her of the suffering she had seen her older sister go through, some years previously, when she visited her in Italy. Her sister also had breast cancer, and the treatment weakened her immensely. Thus, not only Ludmilla, but also her children appeared in her report, as if all were relieved that she would not need to undergo this treatment: *"And she suffered a lot. And my children just wanted to know if it would be like that for me, too. They all thought that it would, because I also had cancer! She went through chemotherapy and radiation. For me, I'm much better off than she was, like this, without chemo."* (Ludmilla)

3.3.2 Winning one day after another

Since not all the women were spared from chemotherapy, we will begin with the experiences of those who underwent this type of treatment: Loren, Marlene, and Matilda. Next, the overall experiences of all the participants, in terms of treatments, will be discussed. In general, all of the women were going through adversities that stemmed from living with illness, and the consequent routine of care that this brought. Despite their suffering, the women wanted to be cured of the disease, placing them in a situation that encouraged them to fight and persist. The analysis of their reports led to the identification of a number of positionings in face of the circumstances, linked to the process of adaptation regarding the disease, as well as to changes in their identity goals.

In Loren's case, after confirmation of cancer she was submitted to a new exam in order to study the possibility of reducing the extension of the area of surgery: *"(...)'You will do a test again. And if it is positive, first you'll do chemotherapy', the doctor told me. So, basically, chemotherapy would serve to make it smaller! Of course, I would do it, because I would do whatever they told me to survive!"* (Loren). After that, her treatment began. Later, when she was about to finish her last chemotherapy session, with an already-fragile body, her treatment was suspended, with surgery taking place a few days later. The following excerpt summarizes the facts:

> The first four chemos were the ones that took longest. There was one chemotherapy that took between 7-8 hours. And after that, once again I should have received 12 more chemos, but I didn’t manage, because I had skin problems and my entire body was weakened. So, I got sores on the top of my head and on my arms, so that the uncovered places even got wet. (...) And that was very strange... To better explain, for example, it’s as if a really small pimple all of a sudden got so big, reaching all the upper part of my body! And that’s why they called off the last session of chemotherapy, and we waited for me to have surgery. (Loren)

Loren’s report identified her suffering during chemotherapy, with her skin becoming sore and inflamed. However, she tried to adapt, enduring the sores until treatment was suspended by medical orders. She felt she had not overcome that stage as she should have, confirmed by the statement *“(...) but I didn’t manage”.* It was also possible to connect the two cited excerpts, as previously she stated: *“I would do whatever they told me to survive”* followed by *“they* (referring to the doctors) *called off the last session”.* In the conclusion of the above excerpt, she once again confirmed that she was at the mercy of medical opinions. She would have undergone 16 chemotherapy sessions, right to the end, even with a deteriorating body that was full of open sores. Loren had taken on a **contingent personal identity**, most likely unknowingly. She was waiting for the doctors to make decisions, just as she waited before for a diagnosis, holding on for around three months until a new doctor arrived at the clinic she was used to frequenting. External contingencies appear to dictate to Loren the rhythm by which she should conduct herself. As mentioned by Charmaz (1995), human beings create meanings for their experiences based on social interaction, and sometimes their intentions, goals, and behaviors are explicit, as happens with preferred identities that are well understood by the subjects. However, at other times the preferred identities are implicit, and are not declared or understood by those who take them on.

Marlene was not as receptive as Loren when she received her prescription for chemotherapeutic treatment. She was already frightened by the extension of the surgery she had been submitted to for tumor removal. This made her fear that, without chemotherapy, she would risk losing other parts of her body, leading her to submit to treatment. She initially said: *“The breast was entirely removed! I have a scar from here to here* (showing scar). *But, at least, everything that was malignant was removed, that’s what they said. Three lymph nodes were also examined, but they weren’t affected. That was something good in these bad times!”* (Marlene). The excerpt, besides clarifying her mastectomy, showed that she had found something positive in her experience — the non-contamination of others lymph nodes. She continued her report, stating: *“So I was so shocked, because I was soon directed to my first chemotherapy! And I thought that wouldn’t happen to me, as everything had been taken* *out. But I thought, 'better that than losing other parts of my body".* (Marlene) To adapt to this new reality, she had to face her fears and beliefs, stating: *"I thought that wouldn't happen to me."* Marlene showed signs of a **protected identity goal**, as she continued to value her physical attributes, unwilling to lose anymore of her body (and still astonished by the scar on her breast). In addition, she valued her ideas and notions, as she had a few prior certainties which were independent from medical opinion. She resorted to her own internal resources in order to form the idea that allowed her to accept chemotherapy: *"better that than losing other parts of my body".*

In Matilda's report, it was not possible to perceive how she took the news of the diagnosis, and if it brought her fear or resistance, or not. She jumped straight into: *"And then the tissue sample was considered malignant. And so things moved on, with surgery, chemotherapy, and the rest."* (Matilda) However, it could be noted that she went through challenges during the treatment period, as stated at a later point in the interview:

> I had a hard time with chemotherapy, because some people tolerate it well, others don't. For me it was bad, but I have nothing special to say. *(20-second silence)* You have to go through it, so I did! The first four sessions especially were very strong. On the first day after chemotherapy I was doing very well, it was tolerable. And then in the next 3-4 days, I saw what it was like, because a lot of bad things happened to my body. But I also have to do my household chores, so I only stopped when I took short breaks. How can I say this?! It should be like this, that all I had to do was move ahead, without stopping to think. (Matilda)

Matilda could not stop to *"think"* or analyze her suffering, since she stated that she had no time to pause and had to keep moving ahead. When she mentioned *"I only stopped when I took short breaks",* she was referring to the days or hours when she left home to receive treatment. However, she could not rest at home, since she always had her household chores and husband waiting for her. In this excerpt it can be noted that, during the interview, she had to reflect, taking a break think about all the things that had happened to her. At first, when asked about how she dealt with the treatments, she quickly answered that she did not tolerate chemotherapy well, but followed this with *"but I have nothing special to say."* At this point, she remained silent for approximately 20 seconds, as if she was seeking to reflect upon how she handled everything. At last, she concluded, *"all I had to do was move ahead, without stopping to think"*, and that was how she was dealing with the situation. If, for one moment, we consider the hypothesis that Matilda had adopted a contingent personal identity, since she was always answering external demands, such as housework or caring for her husband, then this raises the question of why she adopted these behaviors. It seems as if she was neglecting herself, both in terms of physical limitations and of desires and choices, to cater for these external contingencies. However, it is necessary to examine the role she had as a social actor. She was a 70-year-old woman who had been a homemaker for almost her entire life and had never held a paid position. She recognized and identified with the role of wife, as traditionally stipulated by patriarchal society. Thus, she felt responsible for dealing with her house and, in this case, her invalid husband. Matilda did not manage to reduce her identity goals and, even while sick, adopted a **protected identity goal.**

Melo (2008), when reflecting upon and reviewing the work of Joan Scott, affirms among other conclusions that women, when outside of their natural domain, become undefined beings. However, the action of establishing what would be this natural domain stems from a historically constructed process. Even though this concept of acting is frequently considered a condition of human nature, it is a specific concept, historically connecting the same ideas that denied women their individuality, autonomy, and political rights.

To move ahead, it is important to point out that, for the three women who underwent chemotherapy, the subsequent radiotherapy and hormone therapy treatments were not seen as severe and aversive. However, for the other study participants, getting through these stages was a true battle. They complained of dryness and burns on their skin, intestinal changes, insomnia and drowsiness, excessive fatigue, among other physical and psychic side effects that pushed them into adaptation efforts.

Karen, an 81-year-old woman, suffered greatly from skin issues during radiotherapy: *"Therefore, this radiation therapy pressured me more than the surgery. Because I was there every day, and my skin was very burnt. It was really hurt, which made everything more difficult! Look at this* (showing arm), *it still hasn't recovered."* (Karen) She also shared that she lost 7 kilos during treatment, which she associated to radiotherapy and the use of hormonal medication. The different ways in which Karen reported acting, from when she found the nodule in her breast until the moment the interview took place, reveal that, for most of her existence, she took on an **above average social identity goal**. However, after becoming ill, she had reduced significantly her identity goals due to her physical limitations. This will be discussed in further detail in the next topic.

Layla's experience was painful from the moment of surgery, as she reported that either she was not completely under anesthesia, or she must have awakened at some point in the process, as she was conscious for two of her three surgical procedures. This situation made her feel very ill, both at the time and later, when remembering what took place. After surgery she had localized infections (in the area of the surgical cuts) that needed antibiotic treatment, as can be seen in the next excerpt. This left her feeling frustrated, as throughout her life she had avoided the use of antibiotics and other allopathic medications, being instead a proponent of homeopathic or natural medicine. What follows is a part of her answer, which was long, but has been cut in order to clarify her position:

> As I said, in the operating room, what happened twice was that I was wide awake, and so, I tolerated the procedures badly, since I was conscious. It was horrible! A sensation that the knife was cutting into me and I couldn't react. I felt as if I were in the hands of fate! However, the worst came later, as I vomited a lot after surgery. (...) But I can honestly say that I was obliged to take antibiotics! (...) I wasn't happy about that. At home, after the three times that I was operated, I would wake up in the middle of the night with pain and fever. Ibuprofen wasn't enough. I had to go after my family doctor who, seeing it was an infection, would prescribe antibiotics. And I, who never used them, even for a sinus infection, was completely powerless. Either I had to take that allopathy, or I would die from the terrible infections that emerged. (Layla)

Beyond these complaints, we can see that the fact that Layla avoided chemotherapy, as already discussed, did not save her from feelings of helplessness and lack of control over her own health, and even her own life. Becoming ill with breast cancer and the subsequent treatments placed her at a crossroads: either she accepted the resources of conventional medicine, going against her principles, or she would *"die",* as she states at the end of the excerpt. She was feeling *"in the hands of fate",* not just when she woke up during surgery, but throughout the entire situation. The expression was often used during the interview, sometimes in association with complaints against the doctors and the procedures, and at other times with regard to her own condition, reflecting the impossibility of remaining in control of her health. It was clear that this woman had adopted, for most of her existence, an **above average social identity goal.** And even with all her physical limitations, she had not managed to reduce her identity goals. She was deeply upset, and complained during the entire interview about all that had happened to her: the doctors, the treatments, the health insurance, the taxi (transportation to the radiotherapy sessions), and even the ointment that was used on her body before radiotherapy applications, saying: *"I have experience with cosmetics! And that ointment was garbage, without the nutrient levels that would promote adequate protection. (...) Neither myself nor the others are garbage! I took along my own ointment and showed them what an adequate ointment is".* (Layla)

Larissa, Liane, Louise, and Ludmilla had in common the fact that they received a large amount of support from their children and spouses, who helped in the day-to-day of treatments. For these women, the discomfort and other side effects from treatment were present but were well managed with daily assistance from their families. Larissa shared with satisfaction: *"I had support from my children. I have to say this, because the two that lived near me, they work in the care sector. And they were very good, they explained things about lymph, and also did drainage, bandaging, and cared for the house until I could go back to moving.*" (Larissa) In this woman's opinion, receiving care from her children made all the difference during her treatment. She emphasized that they had professional experience in the care sector, but did not directly say what their professions were. Larissa appears to have adopted mainly a protected identity, but had lowered her identity goals during her illness, which helped her deal well with adaptation. However, as she no longer had any ongoing complaints regarding the disease or treatments, and was free from the hormones, only doing check-ups every 3 months, this suggests she was living through a **reestablished identity goal**. She had resumed her daily chores and autonomy, and believed that her previous self-concept was the same: *"The disease didn't change anything in my life. I was what I am today. But of course, for a while I confess that I felt weak and insecure. So, I wasn't this positive! But today I see myself as super positive again. (...)"* (Larissa)

Women like Liane, Louise, and Ludmilla also counted on support from their children, even though they didn't mention if these had any experience with care work. Liane stated: *"Both my sons and my two daughters-in-law helped me very much. So much that it was my daughter-in-law who helped me at the time of diagnosis, because I had blocked my understanding. She took the lead on things, set up the procedure appointments, and took care of everything."*(Liane) In this case, what stood out was the resistance she felt when faced with the diagnosis, even to the point of feeling anger at the doctor who requested the biopsy. She also reported that she considered refusing treatment, if chemotherapy was recommended. A careful analysis of her reports suggests that Liane adopted a **protected identity goal**, and that she allowed herself to lower her identity goals, which previous to the disease point to an above average social identity goal.

The stories of Louise and Ludmilla were similar: besides the fact that both were immigrants in Germany, their children (and a grandchild in Ludmilla's case) were very present in their reports. Louise's children began visiting her every day, helping prepare food, driving her to treatment, and so forth, providing an important source of support. She said more than once during the interview: *"I live for them!"* Sometimes the phrase was accompanied by the following words: *"Without them I couldn't bear it",* or even, *"What would happen to me without their love?"* In her case, and in the case of Ludmilla, a **contingent identity goal** appears to have been adopted.

Ludmilla’s experience with treatment was also permeated with her children’s support. But things changed in a special manner, when her first grandchild was born while she was halfway through her radiotherapy sessions. According to her, her children were very caring during the process, but she was unmotivated, feeling that she was weak and had gained weight. She feared she was no longer the person she had been before. However, she found new enthusiasm: *“I noticed I gained a few kilos. I got fat and weak at the same time. I felt different. (...) And I also felt a lot of pain. And I can say that all that made me sad! But that’s when my little grandson was born, and that helped me a lot in my recovery.”* (Ludmilla)

Lisa, like Matilda, appeared at times to live with a contingent identity; in her case, mainly due to her revelation that she was sad that no one (her children) was supporting her in her fight against the disease. However, even though she had slowed down, she was still managing to achieve the tasks she set herself, such as caring for her house and her father’s house (an 88-year-old man) and doing her mother-in-law’s laundry (91 years of age); this revealed she had taken on a **protected identity goal**. She did not seek help from her siblings or their spouses to deal with her father and mother-in-law, and this had burdened her further during her illness. Lisa’s husband did opt to place his mother in a nursing home, which helped relieve some of this burden, but not all of it, as she was still washing her mother-in-law’s clothing weekly. Additionally, Lisa had received a fright not long before the interview, as she had found out her pension had been denied by the social security department, and she would have to go back to work. In her words: *“I’m from the time when women didn’t have to worry about themselves. They went doing what was in front of them and had to be done. As I lived in the countryside, I even helped my father with clearing land. But I can’t do this anymore, because I’m limited. (...)”* (Lisa) She added, helping clarify her fears of formal work: *“Just remembering the clicking sound of my boss’ shoes, who would always come and watch what I was doing, I get chills! I already did things at my own rhythm, and now that I’m sick, this rhythm is slower. She, or someone like her, will destroy me if I have to go back there.”* (Lisa)

Melinda, on the other hand, counted mainly on her husband but was often visited by her two daughters and granddaughters, mentioning that this cheered her up immensely and helped her renew her hopes. Her identity goals do not appear to have been shaken, and she maintained a **protected identity goal,** despite having to set aside some of her Church-related tasks, as she felt she did not have the same energy as she did before cancer**.** Mia, who appeared to have been previously very active and productive, managed the situation mostly by herself. She demonstrated that, despite having lived with an **above average social identity**

goal, she had managed to reduce some of her expectations, helping in her adaptation between self and body, as will be discussed later.

3.3.3 Dribbling exhaustion

Excessive fatigue was a theme that permeated all of the interviews with the German women. The subject emerged as the biggest challenge they had to deal with on a daily basis. Independent of age, from Karen (the oldest participant) to Loren (the youngest), the biggest reported side effect of the experience of dealing with cancer treatments was loss of energy and well-being. The following excerpt — Karen's experience — introduces the theme:

> Everything changed for the following: I'm a very active person, I was athletic, but for over 10 years I've had cardiac arrythmia. And this of course has limited me. However, with these cancer treatments, now I'm more knocked down! I always liked doing sports and taking part in competitions. I climbed Mount Kilimanjaro a few times, and I was really very active. (...) I already could no longer do that, climbing for example, because of my heart history, but I still did other things. Including cleaning all my house by myself. I've been doing yoga since the 60s/70s and I kept doing it. But now, that changed with breast cancer. I was already a bit reduced before, limited. But now I do almost nothing, from a complete lack of physical conditioning. (Karen)

Karen had been an athlete, and had even climbed Mount Kilimanjaro, in Tanzania, several times. However, she stated she had stopped competing or practicing high frequency sports some 10 years before the interview, when she found out she had a heart problem. But until becoming ill with cancer, she had kept up her yoga practice and her walks, and she had managed all her household chores. As mentioned previously, Karen appeared to have predominantly lived with an **above average social identity goal**; however, with the process of aging and the arrival of breast cancer, she lowered some of her expectations. Among the words she used in the previously cited excerpt, a few stand out, such as *"reduced"* and *"limited"* — terms she used to define the physical condition she found herself in after developing arrythmia. Additionally, in order to define her physical state at the moment of the interview, she employed terms such as *"knocked down"* and *"complete lack"*. This helps us to better understand her daily efforts to deal with the frustration of not being able to walk a few blocks to go to a coffee shop, or simply not being able to stay awake to watch a favorite TV show. To adapt self to body, she began giving into her physiological needs by napping after lunch or exchanging walks for activities such as magazine crossword puzzles. She added that this was hard, but not impossible: *"Really, today for instance, I'm well. It's a bit like the* *movement of a wave. Hard to follow, but not impossible! Sometimes you're a bit low, sometimes you're even lower, but you're alive."* (Karen)

Like Karen, Mia also appeared to have had an **above average social identity goal**, and had also suffered a reduction in her everyday expectations. At the time of the interview, Mia had shown herself to have adapted to her new situation, affirming: *"Cancer brought its teachings, and the main one was, that the dishes and the house can wait for rainy weather to be cleaned, because if the sun is shining, I'm going to enjoy a book on the porch."* (Mia) Her story was noteworthy, as she revealed that her standard of living had fallen drastically after she and her husband had retired, some 10-15 years before breast cancer. With reduced financial resources, they had difficulties managing to pay for the necessary medications (the ones not covered by their health insurance) and, at the same time, maintain the large house they lived in, which was built in the past when they were better off financially. All the same, she managed things as best as she could, dribbling the limits imposed by fatigue and lack of money.

The third woman to adopt an **above average social identity goal,** Layla, did not dribble this daily exhaustion, but appeared to have been dribbled by it instead. Her reports always mentioned her difficulty in reducing her identity goals. She was clearly exhausted and very irritated:

> I don't know if it's related to the disease. I started to have an impulse of some sort. I am so restless, or I have become more restless than I was before. But then I notice that I get up early, often before 6:30 in the morning. I could easily sleep in, as I'm retired. But I simply cannot sleep. And sometimes I have to get up at 5:30, because my bed seems like a torture pit. And so, I'm tired at night. But very tired! And that makes me so furious that, at night, I could rip the world apart. But in daytime, I hate being tired. Because this exhaustion drives me crazy! I'm not the type of person who gives into exhaustion, and I'm not going to lie down at midday. I like being who I used to be. I was always very balanced. (...) (Layla)

Larissa, in turn, also complained of the fatigue that prevented her even from watching TV at the end of the day. But she stated that she had recovered in terms of handling her household chores and the other things that made up her routine. She reported that she was never a sports enthusiast, but that she had more energy before getting sick. *"I'm sleepier, and I can say that I noticed I get tired faster. That is, depending on what I did that day (...). I'm from the days when TVs were smaller, and I would watch everything! Currently, I lie down in front of the TV at night, and I quickly fall asleep and that's it."* (Larissa) For her, the **reestablished identity goal** was not compromised by going to bed earlier, which was a system she used to adapt her bodily needs to herself. And she had no issues in recognizing that some days bring more exhaustion than others, or that her body was different from before.

Liane, like Larissa, found resources to adjust the limits of her body to self. Her **protected identity** at that moment had suffered from a reduction in goals, compared to her previous identity, which favored the management of fatigue and her positioning regarding it: *"I cared for my children a lot, and then later my grandchildren. (...) But now they don't need that anymore. And I started needing to sleep during the day, to have some naps. So I ask them to only come over on the weekends, because I don't want any extra responsibilities."* (Liane) She acknowledges to herself and to her grandchildren (and consequently her children) that she no longer wants the responsibility of childcare, preferring to limit visits to the weekend. She no longer wanted the role of babysitter. Another interesting thing is that she decided to retire, as she was self-employed and had already completed her years of contribution to social security. Thus, she closed her studio as soon as she found out about the disease, and soon after started her retirement process. Her afternoon nap and her well-being seemed more important under the circumstances than carrying out some of the roles she had previously.

Lisa and Matilda, both living with a **protected identity goal** that did not show signs of reduction, continued with their lives. And even though they both mentioned always being tired, they did not share what might have changed in their routines in order to dribble these difficulties. The difference here is that Lisa was not as debilitated as Matilda, as besides being several years younger she also avoided having to go through chemotherapy. Thus, she dealt with the same tasks as before, but at a slower rhythm, taking longer to finish domestic chores.

Melinda, another of the women linked to a **protected identity goal**, stated that she started sleeping during the day, which helped to better deal with the exhaustion that stemmed from treatment. She also made a few lifestyle changes: *"I am no longer ashamed of sleeping during the day. I relinquished my ecclesiastical duties to have more time for myself. I am the same, and God knows it well. I don't have to be at the front of things to be a Christian. (...)"* Melinda

One woman who was not yet retired, and who was close to the end of her medical leave, was Marlene. While she was at home, she said she dribbled the exhaustion by reducing excessive household activities and trying to sleep for a few hours during the day. She also maintained a **protected identity goal**, even though she underwent several sessions of chemotherapy and radiotherapy. A detailed analysis of her reports indicated that she suffered reductions in her expectations, especially with regard to the physical losses she suffered. As previously mentioned, she told all the people around her that she had breast cancer, because she lost her hair and didn’t see how to hide that fact. All the same, now that she was about to go back to work, she didn’t know what the future would bring:

> I’m still very tired. Now I’m at that moment where my sick pay is almost at an end. And then you have to decide. I don’t know yet what I’m going to do about work. At home, you can squat down, move, you can go to sleep when you want. This is not possible at work, you can’t leave your post. I am 61 years old, I’m no longer that young girl, so to say! And I’m not reestablished. Let’s see how things will work out, because right now, they are uncertain and imprecise. (Marlene)

Loren, Louise, and Ludmilla, the three women identified as living through illness with **contingent identity goals**, had resumed their work functions. All three said they had adopted the strategy of daytime naps while still at home as a way of dealing with fatigue. But things changed when they went back to work. Loren’s story, however, was different from the others, as her treatment included chemotherapy, and took longer than the other women’s treatments, demanding a longer period of work leave. Her organism was probably also the most weakened, due to the higher intensity of side effects. The three women had, coincidentally, returned to work around 3 to 4 weeks before their interviews took place, and were still adapting to the new challenges. Louise and Ludmilla had a number of complaints, such as a greater difficulty in executing movements they were used to carrying out on the job, due mainly to pain in their arms. However, they noted they were gradually adapting to manage the tasks that fell to them.

In Loren’s case, she referred to her time undergoing chemotherapy: *“Of course, I was always tired, very tired! So, I would sleep, because I simply had no strength left, I was fragile and impotent. Simply exhausted! (...) But thank God I was never that bad, like, I didn’t break, you know?”* (Loren) She had allowed herself sleep, as when faced with feelings of fragility and impotence, this was the resource she found to deal with moments of exhaustion. However, she placed the responsibility for not having succumbed to her illness on God, as she “*didn’t break*”, revealing once again a contingent identity. At the moment of the interview, already back at work, she revealed that she was asking herself questions:

> I feel like I have chemotherapy in my bones. I am not, so to speak, completely recovered. I have to say this, because I need energy and strength to work. I need a lot of energy there! In truth, it’s a job for men, I always knew that. So sometimes I think: ‘Hey, did I do that faster before or did I just not care if it was this tiring? Or do I just not have strength anymore?’ It’s then that I recognize clearly that, I have less strength... *(sad facial expression)* And I believe that it will take a long time to have strength again. (Loren)

The questions that Loren began asking herself suggested that, upon returning to work, her identity goals were confronted by her new physical condition and would probably need lowering. In terms of her job circumstances, she did not appear to condition the responsibility for her well-being to third parties. This change in positioning was identified when she reported that she was asking herself the reason for her excessive fatigue and slowness. Reinterpreting her words, she questioned if this stemmed from heavy activity or if it simply revealed she no longer had her former strength. In this manner, Loren concluded that she was the one with less strength, and that her new physical reality was not going to change that quickly. This indicated awareness of a possible search for a new path — such as requesting a transfer to a role more suited to her capabilities — in order to better manage her new reality.

3.4 Discussing or silencing fear

One subject that was not often present in the interviews was fear of death. Only participants Layla, Liane, Lisa, Louise, and Ludmilla used the terms “fear” and “death” in an interconnected manner, or other words with the same meaning. However, it was possible to locate speech in some of the other women’s interviews that signaled fear, pointing at a concern for the gravity of the disease and the risks of recurrence. Additionally, some interviews showed a clear distress regarding treatments and physical condition, indicating a recognition of being mortal. This subchapter will further discuss the theme.

Among the women, Layla was one who did not hesitate in exposing her fears, both of chemotherapy and of the possibility that her cancer might not be cured. She was open about discussing people near to her who had died from breast cancer, emphasizing the case of a close friend, who she missed a lot. Layla told this woman’s story with a great richness of detail, which helped in better understanding her worry about her own illness. The two had been long-term friends, were the same age, and had even been to mammograms together several times:

> Because I always went annually to Munich to have the mammogram. (...) Because I had a tendency to have the same sort of cancer as my sister, who was diagnosed some years ago. That left me very alarmed. And so a friend of mine, very dear to me, died of breast cancer a while before I could go to the exam. After she got sick, I spent 2 years without going to the exam, because she was with me in the beginning of 2015, when she got the diagnosis. And she was the one who used to drive to the mammogram with me! You see? And that was the last time my friend would do the exam, because she died! (...) And there I was again, in December 2017! And I would have to do the exam alone that time. Because Dr. X had said: ‘Not going to do mammograms will not save you from fears of the disease.’(...) (Layla)

The experience that Layla had with her friend’s death appeared to superimpose the fact that her own sister had dealt with — or was still dealing with — breast cancer, yet had not died from the disease. She explained in another segment of the interview that she believed it was genetic; that it was present in her grandmother’s generation, skipped her mother’s generation, and reappeared in hers, manifesting both in her sister and herself. Thus, due to family history, her mammograms should have been annual. Even so, Layla affirmed she had spent 2 years without showing up for the exam, a period which encompassed her friend’s illness and death, as seen in the excerpt above. She also affirmed that, on the occasion of discovering her own diagnosis, she had only attended the exam by medical recommendation, after the doctor questioned her fears. The facts point to a perplexity suffered by the participant, who followed closely her friend’s diagnosis, treatment, and death; this led her to avoid her own mammogram and, possibly, chemotherapy.

Liane was a participant who talked profusely about her fear of the disease, of chemotherapy, and of becoming impotent, abed, or dependent of others because of cancer. However, she said she had never been closed to anyone who was diagnosed with breast cancer. Her reports stand out because she denied several times a fear of death, at moments where she brought up the theme herself: *“(...) I am not afraid of death, that’s not it. I’ve never had that fear. So I say this, to make it very clear! So I leave that to be decided by the one who is above me. (...)”* She referred to God, making it clear He was above her, and that she confided to God the power of deciding and defining the hour of her death. She continued this train of thought, explaining her position: *“Life is not over because of the disease. And it will only be over when my end arrives. I say that, because I am not afraid of death! I am only afraid of suffering pain and going through painful things like being in bed and dependent on others.”* (Liane)

In Lisa’s report, the word death was used to mention the loss of loved ones, such as her mother or grandparents, who had been elderly when they died. It was also used with regard to the possibility of the eminent death of her father, a man at an advanced age. Thus, this was not directly connected to her experience with cancer, and the risks of death were associated to the loss of older relatives. Fear for her own self appeared a number of times, revealing itself a frequent theme in Lisa’s life in the fight against the disease. The following excerpt makes this clear:

> My main problem is mental, psychological. First the fear, because if you feel something in your body — like I recently had an intestinal issue and then they *(doctors)* sent me back there

> immediately *(to hospital)* — ‘Shit, there won’t be anything’, was what I wanted to think, but I was afraid! You always have an anguish back here *(pointing at her head),* the fear is always there and that changed my life. This fear that cancer could come back or that something new was coming. (Lisa)

This psychological state, according to Lisa, is what was really affected by her experience with breast cancer. She began to fear a recurrence of the disease, and also to think that another cancer could be diagnosed in her body, such as when she had intestinal issues. Although she had simply been sent to hospital due to having diarrhea in her first days under hormonal treatment, leading to dehydration — as explained in a subsequent segment of the interview —, she was afraid she had intestinal cancer. And even though she fought these fears, she couldn’t beat them: *“the fear is always there and that changed my life.”*

Louise talked about different fears — the fear of dying, of suffering uncontrollably, and of making others suffer. She did not spare words in order to expose how she felt and how fear was permeating her new routine: *“(...) The operation was very long, and I was already afraid of not coming back from surgery, of dying right there, on the operating table. When I regained consciousness, in the recovery room, and saw the time, I got a huge fright! It was 7 hours later!”.* She talked about her experience and fear of surgery, a long procedure, that she went through after her diagnosis. She had never been through surgery before, as both her childbirth experiences were natural, so she feared to die during the tumor removal procedure. In another segment she stated: *“I think the truth is that everyone has this fear of dying, because everyone wants to live. So, they might not talk about it, but it’s normal for everyone to have this fear.”* (Louise) This pointed to an attempt at mitigating her own distress, sharing the fear of death with *“everyone”,* and making her own fear something intrinsic to human beings, and therefore pertinent to herself. At other moments of the interview, Louise associated her fears to the fact that she lost a young sister, only 27 years of age, who died due to hepatitis that was aggravated during treatment. She used the loss of her sister as a way of justifying why she did not tell her family in Poland about the diagnosis: *“I opted not to tell my parents that I have cancer. Because I still remember the suffering they went through with my sister’s death. I am afraid to make them suffer with this, awakening a fear in them of losing another daughter”.* (Louise)

Ludmilla, the other woman who, like Louise, was also an immigrant in Germany, shared that cancer had changed her life, as besides making her lose physical strength, causing problems in her daily life, it also brought psychological torture: *“You’re never again who you used to be. It’s about the strength that you lose. (...) It’s about the thoughts, psychic things,* *that are always there reminding you: 'Is this going to recur? Is this going to kill me? (...)"* The excerpt points to a fear of recurrence and of death due to the disease.

Most of the women interviewed, however, different from what has been discussed up to this point, sought to silence their own fears. They camouflaged these fears among words that would give them a different sense, or avoided certain terms, especially if this would provoke tears that should not be shown, or a discomfort they could not deal with. This subject will be discussed in the next topic.

3.4.1 Silencing fears, including of death

To start this discussion, we return to Karen, the oldest woman in the group and also the one with the highest socioeconomic position. She did not mention a single time the words death or fear, opting instead for expressions such as *"that made me feel pressured"* and *"I feel a deep impact"* when seeking to describe the experiences that, somehow, seemed to bring her closer to unspoken fears. In the following excerpt we can identify one of these moments: *"In conversations with Dr. X, I didn't understand even half of what she was trying to say with the technical expressions. That made me feel pressured. But my partner tried really hard, and he would explain my uncertainties, and that would calm me down."* (Karen) She affirmed that when she was not able to assimilate the doctor's explanations, especially due to the use of technical terms, she felt that she was under pressure. It is not possible to affirm that this feeling was fear; however, it did relate to some distress or uncertainty, seeing as she calmed down when her partner clarified the medical jargon, answering her questions about the disease. Another excerpt pointed to one of the silenced fears, when she talked about having used hormonal replacement since menopause and about her suspicions that it may have had implications for having cancer, as well as for the raised risks of a recurrence of the disease:

> I went to the doctor and asked about the relationship of these hormones with my kind of cancer. And he said: *'You had 30 very good years with hormone replacement'.* 'But now I'm paying the price, aren't I?', I asked him. And so he said: 'When women in menopause seek me out, because of the effects of menopause, like hot flashes, I also recommend they take hormones. And so, some of them say: 'No, I'm not going to keep taking hormones!' Very well, each one knows themselves. And so, 10 years later I don't recognize them, because they became wrinkled dwarves. However, you were spared.' *(laughter and laughter)* So, I hope he's right, because just thinking about it, I feel a deep impact on me. And in any case, if this is related to cancer, there is no return now. (Karen)

There is a lot of information in this excerpt, beyond the interviewee's perception of a possible link between use of hormone replacement therapy and the fact that she had cancer. She also revealed how the doctor banalized her inquiries, changing the course of the conversation. When she directed her questions to the professional, he did not confirm or deny her suspicions, instead leading the subject away and into her prior well-being, to the point of highlighting her appearance. In his words, reported by the participant, women who do not adhere to this treatment *"become wrinkled dwarves",* affirming she had been spared from this. Karen, despite laughing when she recalled this conversation, did not seem convinced she really had been spared, as she had breast cancer. As she said: *"But now I'm paying the price (...)"* and adding, later, "*if this is related to cancer, there is no return now".* These phrases indicate her fear of the high price to be paid due to the use of hormone replacement therapy for 30 years in a row.

Karen mentioned that thinking about this made her feel a *"deep impact"*. This leads to an understanding that she would prefer to set this aside, and not even criticize the fact that the doctor did not answer her question. These analyses indicate a manner of silencing feelings of guilt, banishing the appropriation of certainty that the hormones could have caused the cancer. This posture, of not criticizing the doctor's banalization, points to a certain contradiction with her preferred identity, which was above average. This highlights that there was a silencing of her fears, as a possible strategy of self-protection.

Larissa, Melinda, and Mia were women who restricted their fears, beyond the initial fear linked to the moment of diagnosis, which would have already been overcome by the time they were faced with the need to deal with recurrence risks. However, Larissa made a brief mention that indicated how she dealt with herself, silencing her fears during the moments when she was subjected to radiotherapy: *"Honestly, I can say that there, sometimes I would fall into a hole and would ask myself: 'Oh, why me? Will I escape this?' But it so happens that I would repeat rapidly to myself: 'I have always managed to overcome things, and so it will be again.'"* (Larissa)

As for the fear of recurrence, Larissa only made superficial comments, as in this excerpt: *"Of course the cancer remained as a mark, because there will always be a concern that it will return. So, now and then I will have some check-up exams. But I am very well, completely recovered. (...)"* (Larissa) Her posture was coherent during the entire interview, with a logical linearity among the reports, as well as harmonized facial expressions and an unaltered tone of voice. Possibly, as she was done with the hormonal treatments, capable of altering women's moods, and felt her sense of self to be reestablished, her feelings of security regarding recovery had emerged in a different manner to the other women in the study. All this is compatible with the reestablished identity that she appeared to have taken on.

For Melinda, the posture adopted in face of her fears or worries appeared more defensive, as at times it was incompatible with her words and facial expressions, or tone of voice. At least twice she talked in a low and shaking voice, specifically at the moments in which she mentioned having overcome the disease, needing only follow-up appointments. This was not coherent with her reality, as she was still using hormonal medication, which she would need to continue taking for 5 years. As can be seen in her report, which includes the comments made during transcription, she had difficulty saying the final words. This suggests an attempt to camouflage her own thoughts, or to not expose them during the interview:

> I hope that, as I always take the proper precautions, everything will be fine, and I will always hear from the doctor: 'All is well.' That is what is expected, so to say. But, if not, in truth, I live every day as those days come to me. In truth, I live as before. Because at this age, I've already learnt a lot of things, I already know how to live... *(10-second silence and continuing with a low shaking voice)* It's been overcome! I hope that nothing comes back, and that it's enough to go to check-ups. (Melinda)

It's understandable that Melinda might have trouble admitting her distress and lack of control regarding the risks of cancer recurrence, especially as she had adopted a protected identity during her illness. Additionally, to interpret her words, the fact that she believed she had already lived a long time, being an elderly woman, meant she knew how to live. If this was so, a wise person would not be worried, and would not foresee issues in occupying their existence.

Mia's words revealed that her experience was a little more painful, since when she initially cited her apprehension, as if all was well, she soon began to cry. Her subsequent attitude indicated she didn't want to be seen like that, and that the subject should be changed. She changed the theme of the conversation abruptly, without any external motive, asking if she could release her dog, which she had locked away so as not to disturb the interview. If there was a dog in the house, it had not made any noise that could have explained her attitude. In any case, she left her porch for around 5 minutes and returned without the dog she had supposedly gone to fetch. The subject was not renewed, and she began describing her pet's characteristics, indicating that she was not disposed to talk about the main challenges she had to deal with after breast cancer. The following excerpt demonstrates the situation, which was unprecedented:

> (...) So, all is well now. Let's hope it stays that way. I only have to do the follow-up exams, but that is in my own interest. Because I know I'm well. It's always so distant when you hear talk of breast cancer and other things. You get that and say: 'Ah, yes, poor things, sick with cancer!' And then suddenly, you're involved, you're in there, in the same situation. *(Remained silent for 10 seconds. Cried a little. Held back her tears and changed the subject.)* Are you afraid of dogs? (...) *(Left and returned 5 min later without the dog.)* So, she's a female boxer (...) (Mia)

Loren, Marlene, and Matilda were the women who went through chemotherapy, a treatment that brought the most radical changes to their daily lives, especially with regard to physical alterations such as hair loss, skin sores, gastrointestinal issues, and excessive fatigue and weakness. Their reports were noteworthy for the silenced fear of death, and not only a fear of recurrence. This indicates that the phenomenon was linked to physical and psychic suffering, taking on a broader reach due to the side effects of chemotherapy treatment, and leaving these women more exposed to the perception of human finiteness. However, feeling and perceiving this finite nature does not enable a person to speak clearly of their emotions. Both the sick women and their families might have come up against these feelings without being able to express them in words, since reporting certain emotions demands, at times, a period of reflection and thought to process them.

The following excerpt points to a fear of death, even though the word is not mentioned, on an occasion that involved Loren and one of her daughters, who was more often present during her treatments:

> My youngest daughter made me a book, where she registered all of our moments in this fight. And I'm going to show you, because this was very important to me. *(Opening the book full of photographs and handwritten accounts, with dates, made by her daughter).* She photographed my battles, and was there every day at my side, at chemotherapy. Because my other daughter has a baby and couldn't be so close. Often, I didn't see these photos being taken, because I was out of it. (...) On this day here *(showing picture lying in a hospital bed, without hair, in a nightdress, eyes closed, sores on her body, receiving intravenous medication),* I was very ill. When she gave me the book, on the day of my 50th birthday, I had finished my last radiotherapy. And she showed me this photo, saying that after she brought me home, on that day, she went to her house to cry alone. Because she thought it would be the last time we would be together. (*crying*) (...) So, we have overcome this *(disease)* together. (Loren)

In another passage of the interview, Loren made observations about other women with breast cancer who she met during her time at the Rehabilitation Clinic: *"I saw women at rehabilitation who arrived on the same day as I did. They seemed very sad. There was no joy in their eyes, there was really an emptiness. (...) I don't know, it's as if they were zombies. That brought me strange feelings."* (Loren) This segment is worth considering, as she talked about the emptiness she saw in the other women’s eyes, noticing that some of her treatment colleagues were acting like *“zombies”.* These beings, according to popular stereotypes, are living dead; they do not control their own conduct and have no will of their own. By applying empathy, she could have recognized herself in others, especially in terms of involuntary actions, lack of control, or the sense of mortification, but it was easier to say these things about others than about herself.

Marlene used the word *“shock”* often, and in some excerpts this appears to point to her fears, such as that of death; however, she expressed these thoughts while avoiding the term “death” itself: *“You couldn’t say anything to me, or ask me anything, because I would start crying immediately. I suffered a shock, having developed a fear of everything around me. Fear of talking, fear of suffering, fear of living or fear of not living.”* (Marlene) And since her experience with breast cancer began when accompanying her daughter-in-law, a young woman who was dealing with the disease, when Marlene received the same diagnosis this state of *shock* that emerged appears to have followed her for a long while. The word *“fear”* was then used, as something that stemmed from *“shock”,* and which brought the theme of living or not living, as seen in the excerpt.

Different from participants Loren and Marlene, Matilda did not speak spontaneously of her experiences. She acted in a reserved manner, without detailing situations from her day-to-day with the disease. She restricted herself to answering the questions, often remaining in silence a while and then speaking again but with some avoidance. At one moment she mentioned having discovered a new tumor, but soon affirmed that this had no relation to her breast cancer:

> I only have to go to the hospital now for something else. In Kaufbeuren, with the tomography, they found that something is stuck in the pancreas. A cyst or a small tumor. *(10 second silence)* But this is completely independent from breast cancer! The saying is: ‘Those who seek, find.’ But sometimes that’s good, if you find something wrong early. Well, sometimes, it can be that it’s too late. And if that’s it, then there’s nothing to do. What’s your next question, please? (Matilda)

There was a clear denial that the tumor in her pancreas could be associated to breast cancer. This can be explained by presuming that Matilda had no information on metastasis, as this was the closest hypothesis to the woman’s social reality. Maybe this was a form of escaping a discussion of the subject, but this hypothesis is overruled as she went on to say, *“Those who seek, find”*, which suggests she found the tumor by doing exams. Like the other two women, Matilda did not mention the word death in any of her reports. However, at the end of the cited excerpt, she stated that if something in her body was found too late, there would be nothing that could be done. This made it clear that she considered that if death arrived, she would be resigned to it. Soon after this, she took control of the situation, ending the subject and requesting the next question.

3.5 Defining the concept of health

A theme that stood out among the three participant groups, K, L, and M, was of the concepts of health that the women brought with them. By health, they predominantly understood good physical condition; autonomy; the practice of sports or activities such as walking; daily care with diet; the habit of not having vices such as smoking, alcohol, or drugs; being able to enjoy leisure moments; and sleeping well. Participants Layla, Liane, Lisa, and Mia, who had in common their educational level, also added: the consumption of natural herbal teas; the choice of unprocessed (industrialized) food; and the use of homeopathic medication. Karen and Larissa, despite their high educational levels, similar to the aforementioned women, did not include these last items in their reports.

Some of the women — Loren, Louise, Ludmilla, and Matilda — considered they had a hard time enjoying what they thought of as health, even prior to breast cancer. Loren shared that, since she had failed the *Ausbildung* final, where she was studying to be a hairdresser, she found herself having to forgo her dream of graduating and instead seek out a job in a factory. The profession she exerted from that moment was heavy labor, usually carried out by men; however, she persevered because she felt she had no other option and needed a job. This led to Loren developing rheumatism, which she associated to the physical aspects of her job, and which she was already battling prior to cancer. In a similar manner, Ludmilla, who came from Italy with only a high school education, said she had only managed a factory job as a machine operator. She considered that the daily effort demanded by her job over the years had deprived her of being able to enjoy free time with her family, as she spent her leisure moments sleeping or doing household chores — an exhausting lifestyle.

Louise was especially distressed as she considered that her cancer could have been avoided; she thought it had stemmed from the smoking habit she had acquired in her teenage years and that she had not managed to rid herself of, even when dealing with cancer. Matilda, on the other hand, believed that older people could no longer enjoy a good health, as they would always have small problems that would get in the way. Thus, independent of attitude, Matilda connected health problems to the burden of age. The following subchapter will examine the different attitudes and concepts of the women regarding health.

3.5.1 Conditioning the body by means of walks and other exercises

The regular practice of some form of physical activity was considered, by the majority of those interviewed, as important to the women in their social circles. The answers to question number 6, which had more than one sub-question, were significant and complex. Therefore, the question has been translated for clarification: "In general, how do you perceive the relationship of women with their bodies in Germany? Do they take care of themselves? Are they vain? Do they exercise or practice diets? Is figure (appearance) important to them or not?"

In first place, it is worth noting that none of the women answered directly about other German women, in terms of a more generalized perception. Their answers were always preceded by the explanation that they could only speak about their restricted social circle (daughters, friends, sisters, neighbors) and themselves. To shed light on the phenomenon, we will examine the answer of one of the participants, which is in agreement with the other statements given in all three participant groups: *"I must honestly say that, I'm restricting my answers to this question to observation in my circle of friends. I'm not capable of answering what I think of German women, but what I see among my German acquaintances, that yes, I am capable of speaking about. (...)"* (Marlene)

In second place, only two women admitted they were vain, and saw vanity among their friends. They added that they continued to make an effort to be attractive, even though they had to change some of their habits, aiming at preserving themselves while dealing with breast cancer treatment. These participants were Karen and Liane. An excerpt from Liane's report points to her choices regarding appearance:

> I no longer dye my hair as I did before, every 15 days, that would be too much pressure. But I use a spray that camouflages the gray hairs, so I can keep looking young and attractive. I admit that I'm vain, just like my friends, my daughter, and my daughters-in-law. (...) I also don't go to the gym anymore, but look at that treadmill and that exercise bike *(pointing to the equipment in the living room)* — I apologize that they are there, in the middle of the living room, but I train at least twice a day, doing at least 30 minutes. I like to keep up my conditioning. I do that while I watch the news, and so on. My clothing size jumped from 38 to 40 with this disease, but I'm not going to let it go up anymore. (Liane)

Liane liked wearing her hair brown, so before cancer she dyed it frequently, hiding the gray strands. From the beginning, in dealing with the disease, she reduced her salon visits, using instead a daily spray to hide the color of the strands. She associated her desire to remain attractive to this, recognizing her own vanity. Likewise, despite not being able to frequent her gym, she used home fitness equipment at her own rhythm, in order to keep her body in good physical condition. This wasn't only linked to a preoccupation with health, but also to her figure, as she didn't want her clothing size to go up any further. According to her, the weight gain was due to use of the hormonal medication Letrozole, prescribed as a preventive for cancer recurrence. Similar to Liane, but without the same physical state that would allow her to exercise her body with conditioning activities, participant Karen revealed that she sought to care for her appearance. She stated that she no longer had the strength or disposition for physical exercise, but still tried to go for massages a few times a week to maintain a certain balance in her body: *"I'm vain, like I said! I go to lymphatic drainage massage around twice a week. This is the only thing I can do for my body at this moment. (...) But at least, with this, I don't end up thin but full of flaccidity, or with a prominent tummy.* (laughter)*"* (Karen)

A third point in this topic is that the other 10 (ten) study participants did not speak about vanity, mentioning nothing on this subject regarding either themselves or other women in their social circle. Among these participants, attention to body shape was present in the lives of most of their acquaintances. This was also a reality for some of them; however, attention to physical shape was restricted to health aspects, and not directed to associations of weight and beauty, or body and vanity.

Larissa, Layla, and Ludmilla said they felt a little overweight, but the first two did not seem worried, affirming that this weight gain did not bother them, and had only changed their previous size by a few numbers. The last appeared to be going through a period of dissatisfaction with her weight. Layla added she no longer had the same energy as before she got ill, when she could go out on her bike for many kilometers, with a strong and conditioned body. But she mentioned that she still biked near her house every now and then. These 3 (three) women sought in their regular walks a manner of reducing sedentarism and improving physical wellness. However, they treated this as moderate activity, and not sporting practice. For them, these were moments to breathe fresh air and improve their circulation, improving their health.

At one point, Larissa criticized her neighbors, especially a few who were around 80 years of age, and who ran every day and practiced different types of restriction diets. She felt that these were habits that, despite being considered as pro physical health by those who adopted them, were much more likely to be linked to some sort of ill-resolved psychological issue, as they seemed like sacrifices. The following segment clarifies her thoughts:

> I don't practice sports, even though in my social environment there are several people, even elderly ones, who do. My neighbors, for example, there's one who is 80 years old and is very much about fitness, so to say. But that's not so extreme now, because she doesn't do sports marathons as before. No, for the love of God! For example, another one who is 79, with her strict diet, she doesn't eat much meat to be healthy. (...) I don't think that to be healthy a person needs that much sacrifice. There are some excesses in the idea of a fitness body, which in truth should speak of an obsessed psychology. For me, walking a few times is enough for my health. A person should have a balance among their own choices. (...) (Larissa)

Ludmilla, different from the others, not only worried but suffered from weight gain, as this brought daily discomfort such as excessive sweating, shortness of breath, and high blood pressure. She considered that staying home from work for cancer treatment, which made her suddenly sedentary, together with the hormone treatments and her prior hypothyroidism treatment, brought a 12-kilo weight gain in a 15-month period. When she reported this weight gain, she cried a lot, complaining she would not be able to return to her old body shape, a factor that she considered to be her greatest challenge in dealing with the disease. In her words: *"(...) I think the tendency is to get worse.* (crying) *These hormones that I'm taking make me gain weight, that's worse than cancer for me.* (crying and sobbing). *I don't know what to do to get thin, because I also have a low thyroid function.* (crying)" (Ludmilla) This pointed to a distress that stood out in her fight against cancer, linked directly to her inability to control her body weight. She believed this was connected to hormonal issues, and did not mention dietary habits, or the practice of sport with the aim to helping lose weight.

Lisa, Marlene, Matilda, Melinda, and Mia did not talk about changes in body weight due to treatments. Another point in common touched on body and aging. These women had similar ideas regarding this subject; they believed that, the younger the woman, the higher the preoccupation with physical shape, while the older the woman, the less she was likely to worry about this. Two excerpts follow to help clarify these points:

> (...) I think that you, younger women, do this better than us. *(Pointing to the researcher and then to herself).* You take care of your bodies. You do physical exercise and think of yourselves, of your figure. It wasn't shown to us, in our generation, that the self is also important, that the body should be considered important for people to be healthy. Young women do that in a different way. They seem to think a little bit more about themselves. It's a generational change, in my opinion. (Lisa)

Lisa was not that old, as she was only 59 at the time of the interview. However, when she spoke, she positioned herself as if she already felt very distant, in terms of generation, from the women who still enjoyed their youth. As she stated, she considered the existence of generational differences to be significant, with younger women acting differently about their shape (physical body) than older women. She associated the phenomenon of caring for the body to a sort of teaching transmitted to more recent generations. At this point, a new question was directed at Lisa: *"But you said you ride a bicycle and also walk a few times a week, wouldn't that be a way of caring for your figure?"* (Researcher) And her response denied this possibility, claiming it was habit: *"Yes, I do this because I was always like that. As I grew up in the countryside, we had to move to come and go. (...) So, I still like that, moving my body. But many women train their bodies because they care, not out of habit, which is my case."* (Lisa)

Melinda, showing a similar perception to the one adopted by Lisa and by some of the other women, cited the example of her daughters, one of 43 and the other of 41 years of age, comparing them to each other and to herself:

> I have two daughters, and I see that they worry a lot more about their bodies, than I worried about myself when I was young. For example, the oldest is always in appointments, she goes from doctor to doctor and is always taking care of her health. The youngest trains heavily at the gym and takes part in several marathons. In our generation, we didn't do that! I only went to the doctor when I felt something like pain, or that wouldn't heal on its own. I also never did marathons, even though annually, I believe I reach my 10 thousand kilometers! *(laughter)* If I add all my walks, which I do every day in the nearby woods, and also my Church pilgrimages, (...) I'm not far from that! *(laughter)* (Melinda)

It's interesting to note that Melinda brought something new to the idea of generational differences, introducing to the discussion the fact that one of her daughters spent a lot of time in exams and appointments with health professionals, while the other is a semi-professional running enthusiast. This shows that, within the same generation, women can adopt different practices that demonstrate their care for their bodies and health. Something else that stands out in this excerpt are the daily walks that are a part of Melinda's life. She goes into details in another segment of the interview, saying she developed the habit in her youth. Her words identify this as a strategy used to maintain physical fitness, because of her job as a seamstress. As she spent many daily hours working seated, she set herself the goal of walking every day for an hour after lunch for physical well-being, and even though she was retired she had kept up the habit.

One phenomenon noted were the frequent religious overtones among many of the reports from different German participants, with frequent talk of pilgrimages, promises, prayer groups, and Catholic Church mass. This will be discussed at a later moment; however, it is worth mentioning at this point since Melinda was not the only one to speak about long pilgrimage walks. Other women also said they took part in pilgrimages, walking long distances for their faith, which demands a good physical conditioning. For instance, Liane and Loren also mentioned similar pilgrimages to those of Melinda. These women had already walked the Camino de Santiago de Compostela[8], and also, whenever possible before getting sick, they would take the path from their homes to the Saint Crescentia Monastery[9] in Kaufbeuren.

Finally, both Marlene and Matilda, as well as Loren, who all underwent chemotherapy, said they were not even going for walks at the time of the interview. According to these women, in general, they did not yet have the physical stamina for this. Loren said she tried to go to the Saint Crescentia Monastery, driving part of the way with her daughter and then, at her insistence, attempting to walk on foot. However, she was obliged to sit and wait for her daughter to fetch the car, as she felt very ill and breathless, giving up on the outing. Matilda, in turn, mentioned an absolute lack of time that, added to indisposition, stopped her from doing certain things for herself, such as going out for walks.

Contrary to the last women cited, and different from the rest, Louise was an exception, as she was not submitted to chemotherapy. And even after radiotherapy, she was experiencing a certain physical vigor. Therefore, not only was she back at work, but also at her training sessions at a gym she frequented before getting sick.

3.5.2 Choosing which products to consume

Among the reports of most of the women in group L, and also of participant Mia, specific mentions emerged of choosing food products for themselves and their families —

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[8] The Camino de Santiago, or Way of Saint James, is taken by pilgrims who wish to reach the town of Santiago de Compostela in Spain, walking different possible routes in Europe. Some people walk the route for faith, while others do it to win the Compostela (a symbol associated to the apostle James) (Diários de Compostela; 2020)

[9] Sister Crescentia was a nun and nurse who lived in Kaufbeuren (1682-1744) and was beatified by Pope Leo XIII in 1900. On 25/11/2001 she was canonized by Pope John Paul II. Her monastery in Kaufbeuren is known as the Saint Crescentia Monastery (German: Crescentiakloster) in her honor. The place receives many annual pilgrimages from the Saint’s faithful. (Katakombe.org; 2020)

especially their spouses, who they ate meals with regularly. Some also cited the search for vitamin complements, complaining that their health insurances did not cover that sort of medication, as can be seen in the words of Mia and Lisa: *"This illness is very expensive! The health insurance does not pay for vitamins and does not care if we have money to buy this medication. We are elderly and we need this. It's a paradox!*" (Mia) Lisa, who had training in the food industry, as she had studied for the *Ausbildung* and worked as a professional cook, complained: *"Choosing food and being able to buy everything right, to have a good daily nutrition, costs money and demands time. 'Quatsch!*' (ridiculous!) *Of course, a vitamin complement is important and helps with cancer. But the health insurance won't pay for it.*" (Lisa)

The reports of Layla, Liane, Lisa, and Mia identify a search for products of a more organic origin, or bio-products, as well as an effort to reduce the consumption of red meat. The use of teas and of fruit juices and smoothies was also cited among the attempts to promote family health. Mia said she'd always liked growing vegetables and herbs, but as she and her husband were both ill, they had abandoned the habit of planting, which led to more expenses in buying these items, considered essential in the couple's diet.

Layla reported she had followed a diet with less meat and more fruit and vegetables since her youth, and that this habit had been cultivated by both her and her husband since they got married. Layla, Mia, and Lisa also spoke about the use of homeopathy and of flower remedies, always prescribed by private health professionals who worked in naturopathy fields.[10] These women also complained that this was not covered by their health insurance, as they felt better after use of flower remedies and other naturopathy prescriptions.

Loren, different from the other women, reported that she felt guilty because, since becoming ill with breast cancer, her taste had changed, and she was consuming more sweet or sugared food, which was not a habit of hers before treatment: *"(...) As I said, I developed a strong desire for sweets instead of something salty or spicy. Yoghurts, rice pudding, chocolate puddings, and other sweets, have practically become my diet, and so, also my husband's."*

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[10] Work as a naturopath in Germany is regulated by the "Law of professional practice of medicine without order" *(Heilpraktikergesetz),* which stipulates that it is necessary to have a permit to work as a naturopath. As most naturopaths are not doctors of Medicine, most health insurances will not cover appointments or medication prescribed by these professionals, with a few exceptions such as acupuncture used for chronic pain. Homeopathic medication prescribed by professionals with a medical degree are covered by the different health insurances. (Deutsche Heilpraktikerschule, 2020)

(Loren) She was trying to return her daily diet to her former habits but had not yet reached her goals.

Participant Marlene did not talk about food choices or restrictions but revealed she had banished cigarettes in her home. She considered this was a horrible habit that was bad for people’s health. And even though she and her husband had never smoked in their lives, they had been passive smokers, due to the use of tobacco products by their children and their friends. In her words:

> For me, the great problem of youth, or at least of most of them, is always smoking. For example, I don’t want to offend anyone with this, I don’t know if you smoke. But my husband and I never smoked, and since I discovered cancer, I don’t allow anyone to smoke inside my house. I say that, because my children are also smokers, as well as my daughter-in-law and son-in-law, following the tendency of their circle of friends. We become passive smokers. And then, when you acquire a serious disease, you think: ‘Why do you have to do that to yourself?! Just self-harming yourself with something like cigarettes?!’ But while someone is healthy, they don’t think about that. I can’t control them *(children)* and change their thoughts and habits, and that makes me sad. (Marlene)

Marlene’s observations fit the findings of research by Mauz and collaborators (2018), promoted by the RKI, that identified the consumption of tobacco products as one of the biggest public health issues in Germany. According to the study, cigarette use is the biggest factor of avoidable risk for a large number of serious diseases, including cancer. Consumption of cigarettes, cigarillos, and cigars has been the cause of some 121,000 yearly deaths in Germany alone. The authors’ research shows that actions such as the raise in tobacco taxes, publicity bans, age restrictions, and smoking restrictions in certain locations in order to protect non-smokers by avoiding passive smoking, have not changed the habits of a large portion of the population. Thus, reducing tobacco use continues to be one of the central goals of the country’s public health policies.

3.5.3 Understanding rehabilitation for breast cancer

Rehabilitation, or *Reha*, as the interviewed women referred to it, was a subject brought up by all, either explaining how they had gone through the procedures of the process or talking about how they had avoided it. There were also those who complained they had not received authorization, from their health or welfare insurance, for this kind of treatment — in this case, hospitalization in specialized clinics, without additional costs for beneficiaries.

The subject demands, first of all, a brief contextualization of the term adopted by the Deutsches Krebsforschungszentrum (2018, p. 1): *“Rehabilitation comprehends general measures to reduce the physical, mental, and social consequences after the discovery and the receiving of treatments specific for cancer.”* Additionally, the Deutsches Krebsforschungszentrum (2018) cites that it is necessary to clarify that the aim of rehabilitation is to reduce patient complaints, since going through stressful treatments can lead to the development of other health issues. In sum, the surgeries, radiotherapies, and chemotherapies used to treat breast cancer can generate a need for rehabilitation, for an overall improvement in the quality of life of women facing this disease. In terms of surgery, especially when lymph nodes are removed along with the tumors, there is a risk of developing lymphedemas, demanding drainage and physiotherapy which are carried out at *Reha*, explains the Deutsches Krebsforschungszentrum (2018). Another problem is reduced mobility in shoulder joint, a common issue after a breast surgery that extends to the armpit. As for radiotherapy, the main post-treatment consequences include hardening, inflammation, and discoloration of the skin of the irradiated breast. Other consequences that are more unusual include paralysis or pain in the nerves of the arm, corresponding to the irradiated side, which needs to be treated with physiotherapy and occupational therapy. A constant issue regarding the procedures, and that is more frequent among women who go through chemotherapy, is anxiety. This can generate psychological problems that add to the physical complaints, affirms the Deutsches Krebsforschungszentrum (2018), and demands psychotherapy treatment as part of *Reha*. The aims of rehabilitation are mainly to assist patients in alleviating their symptoms, restoring their physical well-being as soon as possible.

Directed rehabilitation begins immediately after surgery, while the patient is still in hospital, and is called primary rehabilitation by health care professionals. Accompanied rehabilitation occurs at additional stages of treatment, such as radiotherapy or chemotherapy. The measures are adapted individually to each patient and their demands, and are defined by a doctor — usually an oncologist — who carries out the role of being the patient’s reference professional. After primary rehabilitation, follow-up rehabilitation can be prescribed, which can take place as outpatient care, especially if the patient wishes and is in condition to attend treatment near their home. (Deutsches Krebsforschungszentrum, 2018).

Reha procedures that take place within a rehabilitation center that specializes in cancer are more focused on cure or the general rehabilitation of the women, especially those who show a loss in physical performance, such as restricted movement, or those women who have psychological disorders, such as heightened anxiety or intense emotional suffering, generally associated to chemotherapy. These inpatient clinics tend to receive both men and women in need of rehabilitation. In the case of women with breast cancer, they arrive after their outpatient treatments and are admitted for an average of three weeks. According to the Deutsches Krebsforschungszentrum (2018), the German pension authority (*DRV Bund)* compiled specific criteria for the rehabilitation therapy of patients with breast cancer. The guidelines list, among other things, that *Reha* must offer: information on breast cancer and other health topics; sports therapies; nutritional counseling and education; lymphedema treatment; psychological counseling and psychotherapy; relaxation training; occupational therapy and others such as art therapy; guidance in social rights issues; guidance in matters of benefits; and measures to support the patient in professional and social integration.

The costs of *Reha* during hospitalization for surgery are covered by the welfare system. Outpatient rehabilitation, however, must be prescribed by a doctor and approved by the health insurance company responsible for the beneficiary's treatment; the insurance company will decide whether or not to cover these costs, which happens for the most part. For *Reha* that takes place in specialized clinics, admittance costs are generally shared between Welfare, which pays most of the costs, and the health insurance, if it happens to be a state company. Patients covered by private health insurance may have to pay themselves for a significant portion of the costs of this sort of *Reha*. (Deutsches Krebsforschungszentrum, 2018)

After this overview of rehabilitation, we can move onto a discussion of the interviewees' experiences with the system, especially regarding procedures that involved hospitalization in specialized clinics.

Karen had a referral to be admitted to *Reha*, however, she refused to go. She said she had managed to negotiate with her reference doctor, who agreed with her that exchanging inpatient care for traveling with her partner could being more benefits for her psychological state. This woman's socioeconomic condition, as well as her level of education, allowed her to choose whether or not to go to the *Reha* clinic. The main obstacle she saw to being admitted was the risk of being close to other fragilized women, which she didn't feel would help her strengthen herself. As she repeated in other moments, she had suffered *"a deep psychological impact*" (to use her own terms) since diagnosis, which intensified with the hardships suffered during radiotherapy, such as burns on her skin and physical discomfort. In her words:

> I was supposed to go to rehabilitation and, as a friend told me, I should consider the possibility of doing a trip, as an option to rehabilitation, since I was going to spend money on this. (...) Because in these *Reha* centers, they bring together all the women who have the same problem. Some can deal with it better, and others are very vulnerable. And if you only stay with these women, especially the most vulnerable ones, that's not helping you get strong. So, I thought about it a lot, and I took the subject to Dr. X, telling her I didn't want to go to Reha. I was also asking her what she thought about it. She said to me: 'What do you prefer?' 'I prefer to go on holiday,' I said. So she asked: 'Where are you going?' 'To the Maldives,' I said. 'That's much better than going to a rehabilitation clinic,' she affirmed. She is easy to talk to. (...). (Karen)

It is worth noting that, while she recognized that her key issues were psychological, a paradox emerges since she did not mention seeking or receiving a referral for professional help in this field. And her holidays in the Maldives do not appear to have helped her in this regard, as she stated: *"And so we went, but I couldn't do very much there! For example, he* (partner) *is a diver and would go out. And I delivered myself to my pain! I was still terribly worried about radiotherapy and its side effects. (...) It was very bad."* (Karen)

Layla's situation was similar to Karen's, however, although she did not need to cover any of the costs of rehabilitation, she did not wish to undergo this sort of treatment. As soon as she found herself free from radiotherapy, she opted to travel with her husband to the Canary Islands in an attempt to free herself from stress. *"I am not simply a 'patient' patient, as I have had a good education. (...) When they recommended Reha, I felt I was being treated like a child. Yes, I was stressed, but the best relaxation for me was to go to the Canary Islands with my husband. (...)"* (Layla)

Larissa, Louise and Ludmilla did not receive this sort of referral. Larissa and Ludmilla were pleased, as they considered that being admitted to *Reha* might be an indication that all was not well with them. But Louise was initially frustrated, thinking she had not been referred to *Reha* because she was a foreigner, and was receiving an inferior treatment to that of German women. However, after insisting with her reference doctor, in her words, *"crying"* and *"complaining",* the doctor referred her to treatment, filling out the necessary paperwork. In any case, the social welfare system refused to cover her costs. And she was obliged to return to work, as she had been considered apt to exert her employment duties. Back at her job, she reflected that *Reha* might not have been a good idea for herself, as previously discussed in 3.2.2. A summary of her reports helps clarify the situation:

> I was upset, because I thought that *Reha* was my right. That I'm not German, doesn't mean I should be treated in an inferior way. I work and I pay social security and health insurance, so then, I deserved everything like the others. I said this crying and complaining directly to the reference doctor at the hospital. That's when he followed the protocols there, to send me to

> *Reha*. (...) But it was all denied in that bureaucracy, and I was obliged to go back to work. (...) And there at work, like I said, I talked to my boss to be discreet, because I didn't want to be treated like my colleague who did *Reha* and became this poor little thing around there. (Louise)

The interesting thing about Louise's experience is that she acknowledged that *Reha* could function as a space for her to talk about her fears and receive the psychological help she considered she needed. Here, Louise was once again an exception, since she was the only woman who affirmed that psychological treatment would be important in her case: *"I wanted for a psychologist to help me, teaching me to get rid of all the fears I feel.* (crying) *I couldn't go to Reha, but I'm going to look for a clinical psychologist that can offer me psychotherapy."* (Louise) The other interviewees did not see psychologists as professionals who could help, despite a few of the reports recognizing that they had psychic issues which were difficult to overcome by themselves.

Liane, Lisa, and Loren were referred to and went through inpatient rehabilitation. These women had distinct experience during the period when they were interned at the respective clinics that took them in. Liane had three individual appointments with a psychologist specializing in psycho-oncology and could have continued her psychotherapeutic treatment as an outpatient, as recommended by the psychologist, but she did not want this. In general, she reported having liked most of the activities, and that she had made the most of her time at the clinic, even striking up a friendship with a colleague, who she had maintained contact with: *"Reha was very good for me. I liked everything. (...) I loved the psychologist, but I wouldn't do any sessions out of there, because I'm the one who knows me, knows myself. (...) I made a friend there, and that was good for both of us. We're still in contact! (...)"* (Liane).

Lisa did not make the most of her *Reha* experience, as Liane did, and said that even knowing she could be invited back for treatment, she would never return to a clinic like that again. For her, it was very hard to interact daily with other sick women, some with breast cancer, others with uterine cancer, and so on. One day she was close to fainting while taking part in group therapy at *Reha*. Due to this, she was sent to do a heart exam, as the doctor on call that day thought she might have a heart condition. However, she claimed to have become ill upon hearing the distressing stories of the other women in the group, who suffered terribly with cancer. In any case, she passed the exam, which did not show any heart issues. She associated these facts to the denial of her retirement request, which came sometime after the incident. Some of the main points of Lisa's reports can be seen in the following excerpt:

> Reha hurt me so much. (...) There were young women there who had both breasts removed, because they were at risk of recurrence. So, I thought to myself: ‘Oh, God no!’ *(sobbing and tears).* It hurt a lot to listen to these women, and other women full of cancer. (...) That’s why I fainted! I couldn’t cancel rehabilitation and I didn’t want to, although I didn’t feel comfortable there. However, the stupid doctor who was there — I have to say that honestly — obliged me to do a heart exam, and so he certified that I am still capable of working 6 hours a day and that, definitely, I don’t have any health problems. He also wrote that I am not psychologically resistant. *(abundant tears).* And that’s why I couldn’t get my retirement. (Lisa)

Lisa was especially desolate as she felt that, in some way, she had been evaluated during *Reha* and consequently judged. When she saw the doctor filling out the documents about her case, which would go to the social security department, she noted that he affirmed her physical condition was good, and that she had no *“health problems”,* but that her psychological state might be problematic. After saying, *“He also wrote that I am not psychologically resistant”*, she cried a lot and began sobbing; as a follow-up, she was asked, *“But what would be the problem, if you were not psychologically resistant, explain this better?”* (Researcher) She immediately dried her tears and said: *“The issue is that I have no mental problems. I am not mentally ill. I’m a normal person, like everyone else. I was just sadder because of all the sick people near me in there.”* (Lisa) It appears that the participant, by psychological aspects, understood mental sanity. Thus, her response was defensive, affirming that she was normal. The facts clarify her distress, as besides the disappointment of having to return to work, she also had to deal with feeling labelled as mentally ill.

Loren and Marlene, two of the women who received chemotherapy, were also referred to *Reha*. Matilda, despite going through chemotherapy, was not admitted to rehabilitation. In this woman’s case, it may have been because she could not be away from home for three weeks, due to her ill and dependent husband; this is merely a hypothesis, as it was not stated by the participant, who only said: *“I was not referred to any rehabilitation.”*(Matilda) In Marlene’s case, she did not describe her experience, only saying: *“I’m still in treatment. I had chemotherapy and, after, this therapy with antibodies and surgery. I was also admitted to rehabilitation, where I could improve from some symptoms, like pain. (...)”* (Marlene)

Loren’s experience was described in detail and showed she had taken advantage of the time spent at *Reha*. She had been initially resistant, afraid of not being able to manage being away from her family and home for that long: *“(...)Being admitted to rehabilitation in February was very good. I was afraid from the start, because I’m very attached to my house, to being at home. I missed my home even in hospital, and was afraid I wouldn’t manage to stay at Reha.(...)”* (Loren) However, she decided to face her distress and, although she suffered at first, she soon observed that her fight brought her a new sense of self-value: *“So I* *would begin to cry and feel that I wanted to go home. But I was strong, and there wasn't a single day I didn't have to do that! I was fighting, and I felt comfortable for winning against myself, remaining there!"* (Loren) Another positive aspect in this woman's experience was that she noted that, despite all the suffering she had been through from diagnosis to that moment, she was somehow in a better condition than some of the people who were in there with her. This led her to believe that she had come out better in the fight against the disease than her treatment colleagues: *"(...) There I met many other women who were worse than I was. Really finished! I thought: 'Wow, you were very lucky or dealt very well with it, with all the things, the chemotherapy, the surgery, and the radiotherapy. So you are a winner!'"* (Loren). Mia, according to her reports, was also referred to a *Reha* clinic; however, like Karen and Layla, she did not accept inpatient care. She gave two reasons for her refusal: first, her husband and dog would have no one to stay with in her absence, and two, the fact that she was dealing with the disease and treatments herself, without help. In her words:

> (...) Some of them (*health professionals*) came to me because of rehabilitation, sending me to be admitted, and explaining that it was because of the 'psyche'. They offered me that, but I didn't use this service. What was I supposed to do in rehabilitation? I have no peace! My husband is not healthy. He needs me and then I also have the dog. Who would take care of them? I feel better at home. That wouldn't help anything, say, for example, if I were admitted for help with the movement of my arm. (...) But then, there I would think about how things were at home. And if some psychologist then said: 'Oh, no! Think of yourself!' I would have to say: 'And how does that help me with breast cancer, thinking about myself?' What helps me is myself, as I know and define my priorities. I am dealing well with the disease myself, I don't need rehabilitation for that. (Mia)

This section from Mia's report confirms the position she adopted, and at the end also criticizes the possible work carried out by a psychologist, if she were to consult one at rehabilitation: *"'And how does that help me with breast cancer, thinking about myself?' What helps me is myself, as I know and define my priorities."* (Mia)

To sum this up, it could be observed that rehabilitation by means of inpatient admittance was seen by some women as positive, and able to help them in some form to manage themselves when facing illness, such as in the case of Liane and Loren, who stated they made the most of the experience. Marlene did not make it clear if the experience had been positive or negative. Some of the women — Karen, Layla, and Mia — received a referral but turned the opportunity down, evading this process. And last, for Lisa, the experience of *Reha* was extremely negative, bringing moments of intense suffering that, in her opinion, could have been avoided. Thus, the different women had different experiences and distinct views of this treatment, which is part of the national guidelines for breast cancer.

3.6 THESIS: letting go of the social role of woman-heroine and making a commitment to oneself

What would be the stereotype of the ideal German woman, according to the interviewees? The question emerged for the researcher several times during the interviews. First, when the women would point out, for instance, some of their own virtues, affirming they were people who liked working, or acting as exemplary mothers, caring for others, and so on. Later, when they talked about their attending doctors, who were, for the most part, women, giving their full professionals names and paying them compliments. At times, the question would come up again when certain of the women brought forward stories of other women, their acquaintances, holding them up as admirable and exemplary — as diligent mothers, competent housewives, good friends, among others.

Lisa was a participant who said: *"A woman is a heroine, because she always has so much more to do than a man. If she comes home from work exhausted, it doesn't matter. She still has to wash the clothes and cook, because she's responsible for that in the family. (...)"* (Lisa) The phrase led the researcher on a search to understand the words, first in a singular manner, and then collectively. Most of the participants, even those who were retired, took upon themselves a series of daily tasks. It became evident that there was a naturalization of a daily overburdening, something ingrained to customs that were socially diffused among German women, who did not criticize their excessive duties.

To introduce the subject, we will begin with the analyses for group M and progress until K, starting with the lower income women and moving on to those with better economic standards. This is important, as an increasingly higher scale can be observed in terms of the women's need to have achieved heroic deeds.

Matilda and Mia, despite being part of the same socioeconomic group as Marlene and Melinda, were women whose overall conditions appeared more precarious, especially due to their sick spouses. Both took on tasks such as: shopping, cooking, washing, ironing, cutting the lawn, cleaning the house, caring for their husbands, and more. They also managed the household budget, paying bills on time, and therefore were responsible in general for the family's survival. Mia had no children and Matilda did, however she did not mention turning to them for help, even while ill. The other two women shared some of their household chores with their husbands, as well as the financial responsibility for their family, as clarified by Marlene: *“I would have the right to retire, as my cancer was very serious and debilitating. But I don’t know yet if I can do that, because my husband and I divide all the bills. If I retire now, we lose a proportional value (...).”* (Marlene) In this group, only Marlene was not yet retired or on a pension, unlike the other women. However, Melinda said she had several ecclesiastic roles, which she considered a sort of *“work for God”*. But she felt the right to interrupt this work due to breast cancer: *“A benevolent women, must always work! Especially when she’s healthy. Ever since I retired, I took on many ecclesiastic roles in the parish, so that was a job. But with this disease, I understood that God wanted to give me a break. (...)”* (Melinda)

Liane also stated that she shared all expenses with her husband, making her different from the other women in group L, who all said they had fewer financial responsibilities than their partners in terms of supporting the household. However, since these financial contributions from the women in group L were a part of the family budget, it was important for them to be able to work and contribute. In this group, they took on as their household chores the tasks relating to the inside of the house, such as cleaning, cooking, and so forth, considering that their spouses should take on tasks such as grocery shopping, gardening, maintaining the boiler, and others of the sort. Also, since the majority were not retired, they had to fulfill their roles outside the home. Only Layla and Larissa had retired, while Liane was waiting at home for confirmation of her retirement. Among those who worked, some had heavy labor professions, working as a machine operator, as a production assistant, and in janitorial work — respectively Ludmilla, Loren, and Louise.

Another factor that came under the list of chores for the women in group L was caring for people who did not live with them. Besides the role of caring for children and grandchildren, mentioned by those who had them, the reports of Lisa, Liane, and Larissa also cited caring for elderly parents or in-laws. Lisa was responsible for the care of two elderly people, who she visited several times a week; Liane had an elderly mother-in-law who she cared for a few times each month; and Larissa had one elderly person she cared for occasionally.

Karen, on the other hand, did not need to care for anyone. She had no children, parents, or grandchildren. Neither did she have to care for her house alone, as she shared chores with her partner, who according to her (and without specifying age) was a much younger man. The couple also had a cleaner who came in some times a week to carry out general upkeep. However, Karen stated she only accepted help from a third party after cancer:

"Because cancer really knocked me down, so I thought it was time to get a cleaner to help here. (...)" (Karen). She also affirmed that her partner had most of the financial responsibilities for the household, even though she had her own pension. Karen reported having lived a life of heroic feats, and age hadn't robbed her of the shine of her former conquests, of which she was proud, mentioning them several times in the interview. An excerpt helps in understanding the things valued by Karen:

> My best friend and I, we've been friends for 60 years, we practiced a lot of sports together, we did everything. All in time: we danced, skied, pedaled, (...). Currently, yoga is in fashion, right? Well we were doing it 40 years ago. All of that shaped our bodies, we were incredible women, intelligent and extremely beautiful. So, in my circle of acquaintances, women are active and vain, and care for themselves. (...) However, no one else goes to Kilimanjaro, because I was the only one who climbed up there to the peak. *(laughter)* (...) To be honest, I believed that my life was lived in gainful stages, as I did many things: I studied, worked, got married, carried out my profession, was athletic and I always sought to obtain excellence in all of my undertakings. (...)" (Karen)

Karen's statements appear to confirm that she had been, or at least felt she had been, a woman ahead of her time, having known yoga before it was widely practiced, and having maintained an attractive body, shaped by sports, as well as being *"the only one who climbed up there to the peak*" of Mount Kilimanjaro. However, she did not place herself alone as an 'incredible' woman, instead including her friend, or even her entire circle of friends: *"we were incredible women, intelligent and extremely beautiful".* She also talked about the tasks and social roles she carried out, including her studies, work, marriage, and expert exercise and athleticism. Finally, she mentioned striving for *"excellence"* in her undertakings, in other words, not only did she live through countless experiences, but was active in carrying out all the different roles, desiring and working toward reaching the top of the podium in all of her achievements.

However, it is necessary to point out that Layla, a woman whose financial situation was not equal to Karen's, but close, also clearly signaled in her reports the search for excellence in carrying out her roles. She also recognized herself as an extraordinary person, with a duty of attaining important social achievements. In her interview, she often spoke as in the following excerpt:

> Everything I do, will always be well done. Otherwise, I won't even enter the scene. My professional ethics and my prior conduct are also in my private life. I am not an ordinary woman, and I know my worth. And this is why I decided to complain with GKV about the taxis here that take sick people to treatment in a private manner and are paid after by the health

> insurance. I acted also for the other retired people, because myself, I don't need that. My husband took me, and we could pay for gas. But I wrote a very precise letter to the insurance company, detailing their errors. I think it's absurd that here *(small town where she lived)* there are no communal taxis for treatments. (...) If they think I'm annoying, it makes no difference to me! I want to solve the problem for many others, especially the elderly, who can't or don't know how to complain. (...)" (Layla)

The sum of the roles that women from the different study groups exerted in their lives demanded from them, for the most part, autonomy, besides physical stamina for the different task shifts and plenty of willpower. The routines surrounding household chores, aid work, church, care for others, and self-care, were not compatible with the limitations imposed by the disease. Also, for those women in better financial conditions, efforts to reach significant social achievements were not compatible with these limitations, mainly due to the physical decline associated with aging, in addition to breast cancer. Thus, in order to reach a balance between their daily lives and their new health conditions, these women had to renounce their role as heroines[11], or at least lower their goals regarding several of their simultaneous roles.

3.6.1 Understanding the social construction of the woman-heroine

Once again, we turn to the question: what would be the stereotype of the ideal German woman, in the opinion of the interviewees? In response, we found that the stereotype of ideal German woman coincides with that of the woman as heroine. For a heroine, there is no interference from physical limitations of the body, as the focus of her existence is in fulfilling her moral duty. The daily fight of a heroine is in reaching her moral goals, especially in terms of carrying out certain social roles, which the German interviewees associated to women's duties. These conclusions will be examined in this subchapter, taking a new look at the reports of some of the women, as well as their previously discussed life circumstances. This section has been organized into topics in order to better elucidate the phenomena, which point to the

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[11] By heroine we use the definition of Campbell (2005) for hero: a being that overcomes innumerable challenges. Campbell investigated many myths to publish "The Hero with a Thousand Faces" and managed to summarize standards of human behavior that served for anthropology and psychology. In this research, we consider the contemporary woman as a heroine, as she needs to deal on a daily basis with innumerable difficulties inside and outside her home, not just for herself, but also for her family. In many cases, the woman also fights for her community, either through her daily job or by political insertion. The changes that have occurred in the feminine universe, that permeated the 20th century and continue to advance throughout the 21st, place women in the social scenario as a true protagonist and not a mere spectator. Their saga demands resilience and the capacity to overcome obstacles, similar to the saga of mythical heroes; thus, the researcher uses the analogy between hero and heroine.

social construction of the woman as heroine, observed at work, in the lines between public and private, in the sense of responsibility, and in social recognition.

The virtue of work. Among the poorest women in the study, Marlene, Matilda, Melinda, and Mia, daily heroic feats were observed, especially in connection to what the contemporary patriarchy has determined to be a woman's duties in society: working within and outside the home. These women considered the act of working to be a virtue, as can be seen clearly in Melinda's words: *"A benevolent woman, must always work! (...)"*. She was retired, and no longer had demands linking work to money. Melinda used this phrase to justify her search for occupation within the Church, after retirement. For this woman, there was an evident association between productive work and good women, revealing the stereotype she had embraced, and which was shared among the social actors in the environment she found herself within. As she subsequently confirmed: *"Women who work are respected by others. Those who do nothing, who are always lazy, are not respected. But that is not common here. All my acquaintances are women who make an effort. (...)"* (Melinda) In Marlene's story, on the other hand, it was observed that she took on without question the roles expected from a woman typically inserted within the contemporary patriarchy — handling the household chores, a job at a company, and also the tasks of being a mother and grandmother. Cancer devastated her in a different way from the other women, especially at diagnosis, as she could no longer care for her daughter-in-law (who had the same disease) and her grandchildren, who were still young: *"My shock was due to the circumstances, I couldn't get sick, because who would take care of her* (daughter-in-law) *and the children?"*(Marlene) As for her paid job, this became an issue that raised doubts for her; although she was used to dividing the household bills equally with her husband, she realized she no longer had the physical strength that her work as a production assistant demanded. However, she had not yet decided whether to opt for a proportional retirement, even after becoming sick, as the reduced financial position could compromise the family's well-being. Thus, she had chosen to return to work and only then make a decision: *"(...) I will only be in a position to know if I can continue my job at the company or not, after I go back there and see how things will be. Therefore, I'll return and see what happens."* (Marlene)

Matilda, who had never held a job outside her house, lived a sort of daily slavery, carrying out her duties of caring for her home and her sick husband. However, she did not appear to recognize the dimension of her heroic feats when faced with the adversities: she had to bathe, change, and feed her spouse, who was a large man. And even with the side effects of chemotherapy, she didn’t claim a single day of rest for herself. As discussed in item 3.3.2: *“(..) But I also have to do my household chores, so I only stopped when I took short breaks. How can I say this?! It should be like this, that all I had to do was move ahead, without stopping to think.*” The woman did not complain about or question her heavy burden, and simply stated she was moving on with her life, as long as she could rise from her bed to do so. Her physical frailty was visible, raising the question of how she was managing to survive all the challenges that life had dealt her, especially in the past 9 months (time of her diagnosis). Another question that emerged during observation of this interviewee was: until when could she survive in that manner? It was as if her work in a domestic context, including her husband, was the biggest reason for her existence, more than her own self-interest.

Mia acted in a different manner, clearly stating that she had worked away from home a lot in the past, having travelled daily from her town to Munich (located some 60 kilometers away from where she lived) for almost 40 years, until she retired. However, at the time of the interview, her house, the garden, and her husband had become her daily occupation. Nevertheless, Mia stated that, with cancer, she was doing what she could and when she could do it, especially regarding cleaning chores, as caring for herself was her priority. She also complained of having lost her economic standards after retirement, considering this a social injustice: *“Society should rethink its values, acting with more fair criteria. A woman who worked like I did, should not retire with such a limited income, which barely covers the costs of food and medication.”* (Mia)

In group L, what prevailed was the value given by the women to their professional lives, without, however, belittling their domestic life. Layla was proud of her profession and considered that her job made her a socially differentiated woman. During the interview, she also stood out by giving very different reports from the other interviewees, since she was the only one who argued against her medical prescription by not accepting chemotherapy treatment. She also criticized the ointment used by the hospital during radiotherapy; faced up to her health insurance company for refusing to pay for her treatments; and, finally, she petitioned GKV at the federal level to review their criteria regarding the taxi service offered to small town patients. Layla connected these attitudes to her professional experience, alleging that work had brought her many virtues, such as knowledge, discernment, and others, and that she felt qualified to fight for social justice.

Lisa’s work story was an uncommon one, as she was in a training course for elderly caregiving when she was diagnosed, which interrupted some of her plans for the future. She wished to take on a paid caregiver position after she retired from her job as a professional cook. In her words: *"So I was very happy with the training to be a 'Pflegerin'* (caretaker), *and had already made a commitment to Mrs. X that, as soon as I retired and had my certificate, I would work at her house as her caregiver..(...)"* (Lisa) For participant Liane, the experience of working away from home had given her the strength to divorce her first husband, with whom she had her 3 (three) children. And it was due to her job income that she was able to support herself and her children. She added that she was on her second marriage of only a few years, as prior to that she had dedicated herself to her profession and to raising her children until they were all adults and no longer lived with her. This excerpt clarifies one of her perceptions: *"My children became very united with me as they recognized from very early on that I lived for them and my job. I worked hard and made all the money they needed. I only married again when they were all grown up and independent. (...)"* (Liane) She described the relationship between the value she gained from her adult children, and the effort she made to raise them alone, working to support them. Liane also explained how she fought to sustain her home while divorced, keeping up the role of exemplary mother: *"(...) Because you know, that a woman who is intelligent, can't put someone inside her home without thinking of the children. (...) So I fought a lot! I learnt a lot and never stopped improving myself as a professional and as a mother. (...)"* (Liane)

Larissa commented very briefly on her professional life, although she made sure to mention how much she had worked: *"My husband and I were very happy, because I'd finally retired, after years on end working. So, we moved to a new house and had plans for the future. Of course, at first, cancer changed some of those plans."* (Larissa) For participants Loren, Louise, and Ludmilla, work was clearly linked to their need to contribute toward their own upkeep and the well-being of their families. However, at times the act of working away from home appeared as a path to the admiration and appreciation of their families. In Ludmilla's words: *"My children value me a lot, and I think it's because I've always worked and with my money, we* (her and her husband) *gave them more. If I hadn't worked, their father would support the house, but we wouldn't have the same comfort."* (Ludmilla)

Karen valued the work she had carried out in the past, due to what it had taught her, as well as for the broadening of her network of contacts, and her financial autonomy. About her job, she said: *"I could construct here, where I live, the biggest part of my contact network, which is very good. This was while I was working professionally, when I worked in partnership with doctors and other professionals."* (Karen)

The line between public and private: For the women interviewed, there was a clear division between that which was in the public sphere and, thus, could leave the more intimate family nucleus, and that which was not, and which should therefore be restricted to a family context. This division became clear when the research identified that most of the women made an effort to hide their diagnosis from acquaintances, neighbors, colleagues, and even their own friends.

Additionally, it was also possible to verify the rigidity that this notion exerted upon individual privacy, as some women revealed that they didn’t like sharing their problems, not even with a psychologist, although they recognized que some of these issues might be psychological in nature; instead, they considered that these issues were entirely their own. And, in the same manner, some of their most intimate conflicts were also hidden from those close to them, as the conduct adopted was of retention, keeping to themselves that which for some reason they judged should not be shared.

It is interesting to note that the themes of sex, sexuality, conjugal life, or sexual life, did not appear in any of the interviewee reports, which may be connected to this stipulated boundary line between the public and private spheres. The literature points to loss of libido as one of the side effects of breast cancer treatment, but the subject did not come up in these interviews.

For a better understanding of the topic of privacy, we will look at some of the reports that stood out from the others — one from each group. In group M, Mia called attention for three motives, linked to the lines she established between public and private. First, she avoided the subject of breast cancer, even with her oldest friends, who had already had and overcome the disease. She alleged that it would not be good for them to pass on their experiences with the disease, as they might cause her fear in advance, as can be seen in the following excerpt, partially cited in section 3.2.2: *“(...) If they told me, for example, that I would have this, this, and this complaint, then I would get scared. And you don’t necessarily need to pass that along. It’s a matter of posture! We are not the type to talk unnecessarily. (...)”* (Mia) In second place, she indicated that she was not comfortable crying in front of the researcher and, twice, when she could not control her tears, she found reasons to leave the scene of the interview. Such as, for example, when she used her dog as a motive for removing herself from the conversation (excerpt from the section cited in 3.4.1): *“(...) You get that and say: ‘Ah, yes, poor things, sick with cancer!’ And then suddenly, you’re involved, you’re in there, in the same situation.* (Remained silent for 10 seconds. Cried a little. Held back her tears and changed the subject.) *Are you afraid of dogs? (...)”* (Mia) Third, Mia criticized the possible involvement of a psychologist, if she had gone to *Reha*, questioning that she did not know if this would be useful for her, if this professional told her to think about herself (cited in full in 3.5.3): *" (...) 'And how does that help me with breast cancer, thinking about myself?' What helps me is myself, as I know and define my priorities."* (Mia)

For group L, we will take another look at Liane's interview, as she did not spare measures in order to hide her diagnosis from those around her. In addition, she made clear to her children which themes she would and would not talk about, and left some of the interview topics for the end, as if to make sure she would not be judged for them. In item 3.2.2, an excerpt explains her main reason for not sharing her diagnosis: *"In truth, if you have cancer, you're labelled as sick and I don't want that! I have cancer, fine, but I have it now. I feel healthy and I want to maintain my privacy. I'm in treatment. I don't want them thinking: 'Oh, poor thing, you're not going to live.'"* (Liane) She wanted to preserve her privacy, and be free from the judgement of others, thus ensuring the identity of a healthy woman within the social environment she was inserted in. What was new in Liane's interview were the points on what subjects she would or would not discuss with her children, as well as her behavior toward them:

> You can't transmit all your anguish to your children, you have to preserve them from your thoughts that might be unreal. Many times, I was afraid of not surviving the disease, for example, when I was very ill from hormones, but I never talked of this with them. Of course, in the beginning *(referring to the moment of diagnosis*), they saw me act without control, because I was in shock. But I am ashamed to speak of it until this day! As much as possible, I tell them what I consider sensible. Because I prefer to suffer alone! I don't even talk to my husband. A mother can't act inconsequentially, she must always analyze the effects of what she says or does, because otherwise, she can cause damage to others." (Liane)

Liane explained that these lines that she drew between what she would and would not talk about with her children were supported by her conduct as a mother, evaluating what to say and what to do so as not to harm her children. We can consider this a socially constructed practice, passed down from mother to daughter within the society she lived in. Thus, even though some of her feelings caused her sadness and insecurity, she opted to go through all of this without sharing with her children or her husband. And the fact that she had suffered a lot when she found out the diagnosis, and had most likely let her children know of her anguish by losing self-control, was still a source of embarrassment.

Another relevant topic in Liane's reports was religiosity, a theme she waited for the final interview question to approach, having first asked if she could talk of the subject before continuing her report:

> Do you have faith? Well, if you do or not, I hope you can understand. I want to talk about something that I consider very personal, so I'm not sure if it will help you in your research. Can I talk about my religiosity? *(Of course, this is your interview, you can talk about what you want — explained the researcher).* I have to say that I had a personal encounter with Christ, when I was around 5 or 6 years old. I wasn't delirious, I had a sort of lucid dream. It was one day, when I was waking up in the morning, and he was there in my room. (...). And from that day on, I started going to Church and never again lost faith. This is why I spoke a few times about God, Christ, and Saint Crescentia, while I was answering you. However, this is a subject that I don't talk openly about, as in Germany, faith and religiosity are themes that are absolutely part of each person's private life. To talk about this normally is considered inconvenient. However, I'd like to tell you a little more, and if we're done, please turn off the recording. (...) (Liane)

As shown in the excerpt, Liane considered that, in her country, talking socially about religiosity was considered inappropriate, and should thus be restricted to intimacy. However, she felt the need to explain her faith so that her interview could be better understood, since at different moments she had cited words such as God and Christ. It is worth noting, also, that she drew upon the description of an episode from her childhood, *"a personal encounter with Christ",* to set the basis of her faith. This need to register how special she was to Christ could only be observed as something heroic in this woman's experience. When the recording was interrupted, according to her request, Liane continued on the subject of faith for another 15 minutes.

For Karen, there was an initial attempt to hide the diagnosis from the people around her, revealing it only to her sister — since her partner had accompanied her to appointments and knew what was happening. However, she was soon confronted by her circle of friends and found herself obliged to tell them she was ill. Additionally, regarding the dilemma between public and private, the theme of *Reha* emerged in her reports, as it did for the other interviewees. Karen opted not to be admitted for rehabilitation so as not to find herself among other fragilized woman, as discussed previously, not wanting to run the risk of worsening her emotional state. She made an important addition, which also fits with the position adopted by Mia and Layla: *"(...) No one is capable of helping others in their own recovery, especially if the problem is emotional. Each person, at least this is what I think, is the only one who has the power of helping themselves, of managing their 'psyche' in their own privacy."* (Karen)

The sense of responsibility: Among the three groups, responsibility was a topic that, direct or indirectly, helped in understanding the social construction of the heroine woman. Some of the reports presented are new, while others bring a fresh look at previously discussed ideas, leading the texts in other directions.

For instance, Mia and Matilda's option to remain at the side of their spouses, even though they were elderly and sick, as were the women themselves, revealed their strong sense of responsibility. Even though the daily life of these women had become more difficult, they did not mention having considered the idea of a nursing home for their spouses. As Mia's words show, both her husband and her dog depended on her, therefore she chose to remain with them, depriving herself of rehabilitation: *"(...) What was I supposed to do in rehabilitation? I have no peace! My husband is not healthy. He needs me and then I also have the dog. Who would take care of them?"* (Mia) In her pet's case, there are institutions that take dogs in and care for them until they can be adopted, if their owners can no longer handle them, but this possibility was not considered by the interviewee. Even caring for the dog was seen by Mia as her responsibility.

Loren herself questioned her sense of responsibility when she found herself in a difficult situation with her oldest daughter and her baby granddaughter. The excerpt describes an episode involving the three, in which, in an act of trust, the daughter handed her baby to Loren, who was supposed to be responsible for the child. However, the grandmother fell asleep or dozed off, and awoke with her daughter's shouts upon returning to the room. Loren, as a grandmother, felt very bad, reporting this to be the *"worst situation"* of her life. She was so distressed that she could not even cry. The following excerpt explains what happened, in Loren's words:

> (...) My family has to deal with what I was doing, and I can't help them. For example, one day I went to stay with my oldest daughter, when I had already finished the radiotherapies. We had lunch and she left the baby with me on the sofa, I liked that! I was excited to be with my granddaughter. My daughter went to take care of her tasks. But I got so tired, that all of a sudden, I slept, my eyes fell shut and I didn't notice anything else around me. The baby was left alone, as if I was no longer there. So my daughter came in shouting and woke me. And crying, she told me she simply wanted her mother back! I felt terrible. It was so bad that I couldn't even cry! That was maybe the worst situation in my life. All I can say is that this hurts me, because it's so strange to come to face with this impotence, this sensation that you've lost your own values. (...) (Loren)

As Loren explained, she dozed off without being able to control it, and her eyes closed from fatigue. When her daughter returned, saying that *"she simply wanted her mother back",* this highlighted for Loren the perception that she was no longer the same mother as before, which meant she had failed at her role. Perhaps her daughter was simply frightened at her mother's 'blackout', thinking that her mother was unconscious or dead, and reacted by shouting and crying, wanting her mother to be with her. However, this idea is merely a hypothesis, as Loren assimilated the situation differently, imagining it to reflect her impotence and her feelings of loss of values. She continued her tale, saying she felt herself condemned by her daughter, as if she were intentionally acting irresponsibly: *"(...) We then remained silent, but I left very upset. I consider that my daughter thinks I am no longer a responsible person as I was before. It is so devastating not to have control of myself!"* (Loren)

Layla highlighted her sense of social responsibility when she talked about complaining to the GKV about the taxis that transport sick people in treatment, requesting improvements in the service. She affirmed that her attitude was not on her own behalf, as her husband would drive her to treatments by car; instead, it was something she did for those who needed quality and efficiency from these services, and would not have asked for it themselves: *"(...) I want to solve the problem for many others, especially the elderly, who can't or don't know how to complain. (...)"* Another moment where her sense of social responsibility emerged was when she complained about the ointment used in radiotherapy, stating that she would take her own, but that she believed that better products should be used for other women, too (discussed in item 3.3.2): *"I have experience with cosmetics! And that ointment was garbage, without the nutrient levels that would promote adequate protection. (...) Neither myself nor the others are garbage! I took along my own ointment and showed them what an adequate ointment is".* (Layla)

Karen's sense of responsibility could be identified, among other episodes, by her experience and attitude in seeking to understand the reasons that led health insurances not to invite elderly women to mammograms or cover these exams. With a possible motive in hands, she began spreading the information among her acquaintances that breast cancer does not spare the elderly: *"Dr. X, who is also an oncologist, has no doubt that the exam is very expensive for the insurance company, as there are a lot of older women here. Age does not protect against breast cancer, the women and the health insurance have to know this."* (Karen)

Social recognition: Most of the reports mentioned admiration for the female health professionals who attended the women during breast cancer. This was not seen when the interviewees spoke of the male professionals who attended them; in these cases, thoughts were restricted to a description of facts. It is supposed that, by means of empathy, the participants could recognize more virtue in other women, in terms of healthcare attendance, then in men. Or, perhaps, that they felt the need to appreciate with positive comments the services rendered by other social actors who, like them, were women.

Matilda, for example, made an important point that indicates how she wished her life had been, while praising her doctors: *"It's incredible that X and Y are women. They are really very competent doctors. (...) In these times, women have a lot more power, which is very different from my time."* (Matilda) In Lisa's report, we find an appreciation for the services of a naturopath, at a time when she was feeling incapable of winning the disease by conventional means: *"What helped me a lot with this disease, besides Dr. X, is that I have a good naturopath by my side, too. She's very sensitive and very ethical, and this has helped me to balance my body and my 'psyche'.* (...)" (Lisa) For Liane, a psychologist made a difference in her life while she was still hospitalized in *Reha*: *"Dr. X is very experienced and she was my psychologist. During the sessions I did with her, her mastery led me to understand that I went through a great shock, but I passed! (...)"* (Liane)

Additionally, regarding this theme, other women were mentioned as admirable people, including friends, sisters, acquaintances, and daughters; people who, somehow, were examples of a conduct to be followed, within certain contexts. The participants made clear, with this, that there was a social recognition that they conferred to other women for certain acts or qualities. For example, Ludmilla praised the women who lived in her neighborhood, saying: *"(...) Here, it doesn't matter if they're girls, youths, or women, all are very dedicated in caring for their bodies. I observe they are very active, since they're small, they take bicycles, roller skates, and they're always moving. This is very good."* (Ludmilla) For Loren, the woman she admired was her youngest daughter: *"She's very special. She studied and got herself a great job. Besides that, she has dedicated herself to me like no one else. It was really her and Saint Crescentia, taking care of me during that time. (...)"* (Loren)

Liane admired her two daughters-in-law — the younger one, who was Greek, and the older one, a German woman who had been part of the family for a long while. The first was praised for the speed with which she had learnt German, and for her resolve in moving countries to get married: *"They met in Greece, when he* (son) *went for an internship. They spoke in English. (...) She* (daughter-in-law) *decided and learnt German very quickly, so she could marry and move here. She acted with determination, which is admirable in a younger woman. (...)"* With regard to her German daughter-in-law, Liane highlighted her resilience, for marrying as a pregnant teenager and yet being persistent, managing to study and achieve a significant career: *"(...) X is the model of a strong woman. She did not give up on herself for marrying young, already expecting our granddaughter. She studied and today works alongside a doctor, as his right hand. She is very well esteemed at her job."* Additionally, she mentioned the help she received from this woman when she needed her help to face the disease: *"(...) She was my mainstay when I, myself, did not accept this disease and did not know how to act. (...) To be honest, she gave me more assistance than my own daughter."* (Liane)

Louise saw in her sister, who had remained in Poland, thus ensuring the opportunity of caring for their parents in their old age, a person with more values than herself: *"(...) I think that people like her* (sister), *who don't move far away from their parents, are better people than I am. I think that from selfishness, when we are young, we make choices that have no return. Now she can care for our parents and I can't."* (Louise)

Layla and Karen recognized some of their friends as admirable people for the achievements they made in their lives. Layla mentioned a childhood friend who had become a dentist, and still managed to have a family, with children and grandchildren: *"And I have a friend who, different from me, had children. I think it's admirable that a person can study for a career in medicine, be a mother, grandmother, and manage it all well. (...)"* (Layla) For Karen, the person she most admired was an old friend, whose relationship with her had already lasted 60 years. What she liked about her friend, besides their shared life of adventures, was her good sense of humor: *"(...) My friend, like me, did not dismiss any sport. Where there was an adventure, there we would be. She is the liveliest person who exists on Earth. Everyone should learn to be as motivated and good-humored as she is! (...)"* (Karen)

Melinda saw in her daughters a model to be imitated. She said they never became involved with drugs, were *"girls"* who were dedicated to their studies and did not bring their parents any worries: *"(...) I am lucky to be a mother to two very good girls. They've lived for their studies and have never brought us problems like the ones you see around today: things like drugs, drinking, or cigarettes."* (Melinda)

In sum, what can be extracted from the reports in terms of the social construction of woman as heroine, are the conducts that the social actors in the study appeared to adopt, or to consider adequate when adopted by other social actors. Thus, the act of working, whether remunerated or not, was held as a socially recognized virtue among the German women interviewed. In the same manner, the posture of setting clear boundaries regarding what was in the public or private sphere was also part of this conduct, whether in carrying out maternity or other roles, such as that of patient, interviewee, and so forth, performing as a social actor in dialectic interaction with other social actors. And these boundaries, when rigid, can also explain the difficulties in accepting help from Psychology professionals that was observed among these women. Another point identified was the sense of responsibility, which for the poorer women appears as part of the family nucleus, and for the richer ones also emerges as a social issue. Finally, we have the importance of social recognition, given by these women to those whose conduct was considered exemplary.

3.6.2 Overcoming diagnosis and enjoying the present: "The dishes and the house can wait for rainy weather to be cleaned"

In a society that values productivity, and among people who consider work as a virtue, it may not be so simple to give in to a sick body and take a nap in the afternoon, or leave the dirty dishes in the sink. Breaking with certain customs and acting differently implies a process of adaptation, demanding modifications in identity goals so that the self can align with the demands of the body.

Some of the interviewed women appear to have managed this adaptation, leading to a better control over themselves in terms of both choices and relinquishment. These women were no longer quite so connected to the ideal of woman-heroine, but instead to their own desire to overcome adversity and survive death. In a way, they also appeared to manage their own health conditions better, revealing a certain well-being when compared to the other women.

Among those who identified with an **above average identity goal**, Karen, Layla, and Mia, there were different positionings, which also showed a better or worse adjustment of these women to the circumstances of their illness. Karen and Mia, for example, demonstrated a better adaptation of self to body; for this to occur, they permitted themselves a reduction in rhythm, taking more moments of rest and applying less self-criticism. Mia's phrase explains her choices: *"The dishes and the house can wait for rainy weather to be cleaned, because after cancer, I discovered that I can sleep when I'm tired, or simply go and read a book in the sunlight when I'm bored."* (Mia) Karen acted in a similar manner to Mia, since she no longer had the same energy as before to clean her house; however, she had enough money to pay someone to do that for her, so she opted to go against her former decisions and hire a cleaning helper. She also reduced the frequency of social gatherings or physical activity, spending more time at home and going to bed earlier than before, in order to feel better. Karen said: *"I learnt to live in the now, I do what is possible and respect what I'm feeling. Today I'm fine, tomorrow I don't know. But that's how it is when you are no longer young and have a serious disease."* On the other hand, in Layla's case, she did not appear to have managed to reduce her identity goals, or perhaps not without severe self-criticism; her situation, however, will be discussed in the next topic.

In the group of women who demonstrated they were dealing with illness by means of a **protected identity goal**, among whom were Liane, Lisa, Marlene, Melinda, and Matilda, some showed signs of having adapted, while others had not managed to adjust self to the physical limitations of a sick body. The reports of Liane, Marlene, and Melinda imparted the idea that, at some point, their suffering had escalated, leading to self-questioning and a reduction in their demands upon themselves. Their posture with regard to household chores or other tasks had changed and, in this manner, they managed to reach a certain state of physical and emotional well-being, even though they still felt ill. Lisa and Matilda had different attitudes; the first will be discussed in the next topic, while the second, at an appropriate moment.

Liane tried to cut back on her former care for her physical appearance, dying her hair less frequently and doing less exercise, which was carried out at home and not the gym: *"And with this* (cancer) *I had to deal with the fact that I am no longer that woman who would bike 80 kilometers, that now I only bike 20 km, and carefully, on the exercise bike. (...)"* (Liane) She also placed limits upon her children and grandchildren, stating that cancer became the priority, and that she no longer had the energy to babysit the children (grandchildren). The disease brought an important reflection, and the awareness that she herself was the only one who could be responsible for her well-being: *"If I didn't use my time for myself, nobody would be able to help me recover my health. My children are wonderful, but they can't sleep in my place.* (laughter)*"* (Liane) Marlene, another participant who set her children limits, banning them from smoking inside her house, for instance, also accepted more help from them, allowing for a certain reversal of roles, which brought her moments of rest and well-being. *"(...) I was always so tired that I could no longer do anything for them* (children). *Chemotherapy drained all my energy. But I could see the good side of that, because they did everything for me: they cleaned, cooked, and coddled me. I felt good about that."* (Marlene) She went on to explain how she felt at the time of the interview and the learning process she went through with cancer: *"Cancer changed absolutely everything! You start enjoying each day more, so to say. I also have grandchildren and everything. So, I see that I have a beautiful life, and that it depends on me to feel that in the here and now. (...)"* (Marlene) Participant Melinda also lowered some of her goals, having, for example, put aside her work for the Church. However, she stated that cancer had not exactly changed her life, although it did bring more opportunity to reflect as well as an appreciation for health: *"(...) I just observe that I have developed more patience for these waves of heat, or for the pain in my bones that I* *didn't have before, which are due to the medication. This makes me reflect upon how good it is to have health. When I walk outside, I allow nature to be my therapy!"* (Melinda)

Larissa, the only woman who appeared to live with a **reestablished identity goal**, clarified how she managed an adaptation between self and body, while still feeling ill: *"I kept myself positive, I accepted things as they should be and believed it would get better, as in fact happened. My family became even more united after this disease, as my children were wonderful with me. This was very good! (...)"*

Among the women who faced this period of illness with a **contingent identity goal** Loren, Louise, and Ludmilla, a reduction in their goals was also observed, however, a number of conflicts emerged in their reports, revealing a greater difficulty in adapting self to the sick body. For this reason, discussion of these cases will take place in the next topic.

3.6.3 Dribbled by circumstances: "I have no choice, I'll keep going"

Layla, a woman who was very connected to her professional past, appeared to be undergoing the process of breast cancer by means of an **above average identity goal**. As previously discussed, she had not managed to reduce any of her goals, for instance, remaining involved with social demands by seeking a solution with the insurance companies for the problem of taxis. It was also observed that she remained in conflict with herself, feeling anger at her new physical condition. However great her effort to understand her illness and to have some control over the new circumstances, her reports revealed a number of subjective conflicts, such as anxiety about her nocturnal insomnia and her daytime fatigue, or irritability for no longer being the same person, for example, for being forced to reduce the distance of her bike rides. In the excerpt, cited previously in full (3.3.3), it is possible to verify this: *"I don't know if it's related to the disease. I started to have an impulse of some sort. I am so restless, or I have become more restless than I was before."* (Layla) She made a point about her subjective restlessness and stated that she did not know if it was related to cancer, or if it was simply a moment of her life in which she was more agitated than before. Next, she complained of her nighttime insomnia and of the fatigue she felt during the day, affirming this made her angry: *"(...) And that makes me so furious that, at night, I could rip the world apart. But in daytime, I hate being tired. Because this exhaustion drives me crazy! I'm not the type of person who gives into exhaustion, and I'm not going to lie down at midday. I like being who I used to be. (...)"* (Layla)

It is possible to understand that Layla used to have a control over her body that pointed to a certain mastery over her daily management of herself. However, with illness, her body experienced failure, which was seen as an obstacle to be repaired or dominated in order for her to have peace, returning to the person she was before. She did not accept her body's imperative to sleep in the daytime, and neither did she accept her insomnia, especially at daybreak, when she could have slept in but could not manage to do so. She was living as if her body had become her own enemy. A hypothesis to explain her difficulties could be regarding her rigidity in dealing with herself, criticizing her own needs excessively: *"So I continue to use, but only on demand, painkillers. This still isn't over, although I hate myself for having to take this medication. I am attacked by these strong pains, repeatedly! (...)"* (Layla) Another excerpt brings a contradictory report, which shows how she was, subjectively, sometimes doing well and other times doing badly: "*I feel very well, except for this pain, there could be nothing going on. (...) As for energy... Energy I no longer have, but because I am also human, and before waking early I would have to have slept well at night. Quatsch! I feel very ill!"* (Layla)

For participant Lisa, a woman who proved to be living through illness with a **protected identity goal**, her conflicts between self and body could be observed mainly in excessive crying, and her reports of feeling disappointed in others, as well as disappointed in herself. She had already noted and mentioned that she could no longer do everything, referring to daily household chores, at the same rhythm as before, as she realized she was slower. However, her conflicts originated in her questions about plans for the future, as well as in blaming herself for suffering greatly in the past with her outside job. With regard to work, she mentioned one boss who pressured her greatly over the years, and as she hadn't managed to change jobs, she associated this to becoming ill. Her words help clarify her suffering:

> I felt that, somehow, I disappointed everyone, as I didn't finish my course and could no longer be a caregiver for the elderly. So, I doubted this *(the diagnosis)* and asked myself: 'Why am I receiving this now? I am not a bad person!' But you think a lot, many things enter your head. And the thought that insists now is: 'What have I done wrong in my life?' And so, I keep asking myself: 'What do I have to change in my life, what do I have to do in a different way?' I have to reduce my rhythm now, as well, I think about the now. (...) But I still don't know how to do that, I'm still going to go back to work. I think I can say then, that I feel disappointed in myself. *(Crying and sobbing).* I have no choice, I go taking it day-by-day, even feeling full of fragility. (Lisa)

Lisa’s experience with illness brought conflict between present moment, past, and future. She believed that something she had done in the past was responsible for the emergence of cancer, and for this reason she asked why the disease had come into her life, answering herself: *“I am not a bad person!”*. However, she thought that something should be changed in her present, such as reducing her rhythm: “*I have to reduce my rhythm now, as well, I think about the now”.* As to the future, she believed she had no choices, and should take each day as it came. As she was soon to return to work, she revealed her fear of this, as already discussed. This is understandable, as she associated work under pressure from a boss to becoming ill with cancer. Additionally, she believed she could no longer accomplish her dream of finishing training to be a caregiver for the elderly, something she considered as disappointing to others (referring to the elderly she would care for as well as her teachers at *Ausbildung*).

Participants Loren, Louise, and Ludmilla shared a common positioning when facing illness, revealing that they had gone through breast cancer with a **contingent identity goal**. These women, for the most part, delegated control of their lives to other people or to external circumstances. Loren, for example, several times mentioned that her youngest daughter, or Saint Crescentia, or God, had held her in their arms so that she might be able to deal with the suffering of chemotherapy. She even began carrying a small bag with medallions and other tokens of her Christian faith that her daughter made for her, as a sort of amulet to protect her during her fight against the disease: *“I was to carry this* (bag) *to all the places I went, to keep me protected: I took it to exams, appointments, and chemo or radiotherapy sessions. Because my daughter made this for me with a lot of love and a lot of faith. So, I could not forget my amulet at all.”* (Loren) Besides faith and her respect for her daughter’s instructions, Loren had demonstrated passivity with regard to the possibility of a cancer diagnosis, taking a long time to discover the disease. After treatment, she became very frustrated with herself, either for not having the same strength as before, or for having no self-control in certain circumstances, such as when she fell asleep while caring for her granddaughter, seeing the incident as an act of irresponsibility. She was incapable of analyzing the event as an isolated incident in which she had trouble managing her tiredness and fatigue, and felt that her daughter had considered her to be a person with no responsibility. Keeping hold of this idea, among other similar ones, made her very sad.

Louise, in turn, cried throughout the entire interview. She revealed she felt guilty for the disease due to her smoking habit, however, she had not cut back on her use of cigarettes. She took a few breaks during the interview, going to her apartment’s balcony to smoke, proving she still had not managed to rid herself of the habit. Although her routine was partially back to normal, as she had returned to work and the gym, where she cared for her body with sport, she still felt the need to keep her children close. The two, a boy and a girl, who were unmarried but lived with partners, had to visit every day, or else she would cry a lot, feeling alone and afraid of dying: *"I now want to see my children every day, as I don't like solitude and am afraid of dying away from them. And I also confess that cancer has brought me a lot of insecurity. If I see my children, I feel more comfortable inside myself."* (Louise) It was interesting to observe that, around half an hour after the interview began, her daughter arrived with her boyfriend, entering without knocking as she had the keys. The mother leapt off the sofa and said: *"Hi my love, I was already thinking that you would not come today!"* Louise cried at that moment, embracing her daughter, who appeared embarrassed at her mother's attitude, asking the researcher to excuse her so she could go to the kitchen and make dinner.

Ludmilla, like Louise, did not delegate to God the mission of caring for her during illness, as Loren did; however, she did delegate to her children and grandson the task of motivating her to remain alive. She demonstrated that she was living through an intense conflict with herself, mainly due to obesity, which she considered the worst challenge of breast cancer. Just like Lisa and Louise, Ludmilla cried for most of the interview, signalizing an emotional upheaval that had not yet passed. Her depressive state appeared to be associated to her passivity regarding her circumstances, not knowing what to do to lose weight. In addition, she also acted with a certain passivity toward the circumstances of her job: *"I am feeling terrible at work. I don't have the same strength as before, and they haven't changed my position. I have to deal with a lot of pain to do the same work as before. I don't know how to solve this.* (crying)" (Ludmilla)

3.6.4 Neglecting sickness — an exceptional case

Matilda, who demonstrated that she went through illness with a **protected identity goal**, seemed to ignore or minimize the effects of the disease in her life. This may have possibly occurred because she had to attend to the needs of her sick husband, and so could not attend to her own needs. Her identities as responsible wife and diligent housekeeper overruled any identities linked to the disease. And despite her words to the contrary, she was clearly unwell, as her physical fragility was visible: *"I am very well, I can affirm I am more able than before, when the lumps were still in my body. (...) With the surgery I got better."* She was very thin (she appeared to weigh some 42 kilos in a body of around 1.58 meters height), her voice was quiet and slow, and she had difficulties in moving, sitting down, or standing, always seeking something to hold onto. Externally, Matilda looked like she was 90 years old, although she stated she was 70 — which matched the birthdate registered in her *Nachsogerkalendar*. Her situation suggested that lack of money and lack of help had taken a great physical toll on the sick participant.

Additionally, and in accordance with that which has already been discussed in other topics, some of Matilda's speech was not adjusted to the facts observed and could be associated to the ideal she had of herself of how things should be. *"I work here all of the days, as a woman always has something to do: I wash, I sweep, I cook, I clean, I never have time for myself. I am always taking care of everything here in the house, because I like everything clean and organized. (...)"* (Matilda). She did everything alone at home and had no one to count on for household chores; in any case, the floor was visibly dirty, the furniture dusty, and there was a bad odor in the area. She was most certainly giving it her best, with the intention of caring for things in the house, but she was not managing to keep *"everything clean and organized"* as she wished. In addition to that, she also had to deal with her husband, who called her several times in 5-minute intervals. Despite not attending to her husband while the interviewer was in their home, she would reply to his calls with answers such as: *"I'm coming!"; "I'll be there in a moment!" "Wait, I'm coming!".*

At one point in the interview, she explained how hard it was to live daily with her bedridden husband: *"I don't know what else life wants from me. See how he* (husband) *shouts! Today I've already given him his bath, his food, I've changed his diaper, and he's had his medicine. But he still moans the whole time. Therefore, I have no peace."* (Matilda)

If there were issues between the identity goals of this woman, in terms of adaptation between self and body during illness, it was not identified. She demonstrated a neglect for her illness, moving ahead as if herself and body were the same as before. The imperative of attending to the immediate demands left her no chance for *"peace",* as she said. Thus, it was hard to imagine that she would win over cancer.

3.6.5 Redefining concepts about women and their social roles: "Let 5 be an even number!"

During analysis of the reports of participants Karen and Mia, who had an **above average identity goal**, as well as the majority of women with a p**rotected identity goal**, among whom were Liane, Marlene, and Melinda, it was possible to understand the manner in which these women questioned their social roles. As their reports were coherent and consistent in terms of the arguments used and the forms of revealing ideas and positioning, we can extract a number of circumstances in which their conduct became flexible, with the intent of achieving well-being in face of illness.

Karen, for instance, revealed her ideas about hiring house help: *"(...) I never wanted someone taking care of that which was my duty, like cleaning things, organizing the cupboards, and so on. In my understanding, that wasn't right. But then I thought: 'Let 5 be an even number, you'll be much better off that way!'"* The participant had to convince herself that it was better not to be such a perfectionist, especially in terms of her domestic duties, in exchange for being *"better off".* Mia also redefined some of her concepts, and so discovered that reading a good book on a sunny day could help her escape from the tedium of the household routine, which could be done whenever she wanted.

Liane opted for retirement, something that was not in her plans before breast cancer. For her, among other reported conducts, the most important thing was to overcome the disease and have moments of peace and tranquility, which she hadn't had until that point, having lived for her children and job when she was younger; now that she was older, she had dedicated herself to her grandchildren and work. Her choices were seen by herself as part of the need for self-care, as her words demonstrate: *"What I would like to say, honestly, is that cancer makes you decide without guilt what to do. (...) If I want to pull through this* (cancer), *I have to be my own priority and not my children or grandchildren."* (Liane) The words *"decide without guilt",* help understand that it was not simple to abdicate, for instance, work, closing her studio; neither was it easy to let go of the role of exemplary mother and grandmother, restricting the daily presence of children (grandchildren) in her home.

For Marlene, as for Liane, it became necessary to question her role of mother and grandmother, always being the caregiver, and to place herself in a position to receive care instead from her children and grandchildren. Also, this woman did not attempt to maintain a healthy role for neighbors, friends, and acquaintances, hiding her diagnosis. Different from the majority of interviewees, after hearing she would undergo chemotherapy, Marlene opted to tell the people around her that she had breast cancer. However, she did not adopt a fragilized role of one deserving of pity. She publicly accepted her diagnosis in order to feel more comfortable since, knowing that she would lose her hair and go through other side effects, she considered it would be worse to try and hide her illness from others. Thus, upon finding herself ill, Marlene became more flexible in defining what would be public and what would be private. The excerpt examines one of her experiences in this matter:

> (...) When my first hairs returned, starting to grow back, I thought they would grow. However, one day outside, talking to the neighbor, I soon saw that my clothes were all dirty, as if they were full of the hairs of some animal. Then I discovered they were the short hairs that had fallen out. At that moment, I even managed to laugh at myself with her, as we said something like: 'Where is the cat that made this mess?' Therefore, I felt at peace for not having to hide anything from anyone. That was good for me. (...) (Marlene)

Melinda, one of the oldest women in the study, brought forth an important lesson she had learnt during her illness, which was to be capable of a flexible conduct in her work outside the home, giving up on her ecclesiastical duties. Although at a certain point she said that, with the disease, *"God"* wanted to give her *"a break",* later she brought new ideas to the theme:

> I thought that, to have a social recognition there at the Church, I should always have an exemplary conduct. For this, besides taking part in prayer groups, I liked being a eucharistic minister *(Church role),* caretaker, lector, showing that I had a personal relationship with God, and that I valued Him by means of my work. However, after this disease, I see that the one who knows what sort of relationship I have with God, is only me, and I don't have to prove that to others. (...) No one knows anyone's heart! It's silly to keep leading these tasks *(ecclesiastic roles).* (...). (Melinda)

From the extract, we can see that illness made this woman question, beyond her need to work in the Church, the social recognition that this would bring her within the community in which she lived. As she stated, she liked to show that she valued God by means of her work, and that therefore she had a personal relationship with God. Nevertheless, she changed her way of thinking, positioning herself critically about not having to prove her faith *"to others".* Another point that stands out is that Melinda was the only interviewee who spoke openly of *"social recognition",* associating this directly to herself. The other participants came close to this idea, but used values that they recognized in other women, holding them as examples to be followed. At times, the interviewees also mentioned the recognition they received from their children, especially when they had worked away from home and contributed in their support. Finally, a broader social support, away from the family nucleus, was not observed within the reports of the study participants.

PART III

4 PART III: CONNECTING RESULTS FROM THE EXPERIENCES OF BRAZILIAN AND GERMAN WOMEN

The socioeconomic differences in Brazil and Germany must be taken into consideration as a first point to compare the experiences of women with breast cancer in both countries. As stated by Bray and collaborators (2018), in recent years, the incidence and mortality rates for cancer have grown across the world, and despite the complexity surrounding the emergence of breast cancer, an aging population is one of the key factors associated to the disease in the richest countries around the globe. Germany, located in Europe, has one of the highest HDI in the world, while Brazil, located in Latin America, has an HDI considered to be high. (Bray et al., 2018) Both countries have high incidence rates for breast cancer. For German women, according to RKI (2017a; 2020), excluding non-melanoma skin cancer, breast cancer is the disease with highest incidence in the country, with 69,220 new annual cases, an estimate that has remained stable since 2016. For Brazilian women, according to INCA (2017), and also excluding non-melanoma skin cancer, breast cancer was the disease of highest incidence among the female population, with a total of 59,700 new cases in 2016. Additionally, INCA (2019) affirms that estimates for breast cancer incidence have remained stable in the country, with the predicted number of new cases for the year of 2019 equal to 2016, following the tendency of recent years.

One noteworthy point among Brazilian women is that, despite advances in screening for the disease, the average age for discovery of a diagnosis went up from 53 years in 2000, to 56 years in 2010, which could be associated to changes in habit for the population, such as reduction of cigarette use, besides populational aging. However, there are geographical differences between incidence rates, which are higher in the south and southeast regions of the country, and lower in the north and northeast. Regarding this phenomenon, we can add difficulties in screening for the poorer regions of the country to correlations that point to a rise in general obesity and in consumption of alcohol, risk factors for cancer. In addition, the south and southeast regions of Brazil have a higher socioeconomic development index than the others, favoring the consumption of industrialized food. In any case, the death rate due to breast cancer grew 33.6% in the country between 1980 and 2016, which can be explained by a rise in diagnoses, even if late. Some 16,000 women die yearly in Brazil due to breast cancer. (INCA, 2019)

Among the Germans, according to RKI (2020) the new breast cancer rates are stable, pointing to a slight drop. The mammogram screening program for early detection of breast cancer, which targets women between 50 and 69 years of age, was introduced in all German states between 2005 and 2008. The program is centered on the mailing of invitation letters, every two years, to all women insured by GKV, explaining the importance of an early diagnosis and of the participation of each one in triage. (RKI, 2017b). Initially, a large increase in the disease was observed, between 2007 and 2010, culminating with a peak in incidences in 2009, when there was a higher number of cases than those currently registered. (RKI, 2020). After 2010, a slight drop was observed in the number of diagnoses, which has been stable since 2016. This phenomenon, known as the peak of the prevalence curve, was also observed in other countries that implemented screening for the disease, as stated by RKI (2020).

According to RKI (2017b), the average age for German women since 2010 is 64 years. The measures of early detection have as their aim not simply to identify breast cancer as early as possible, but to treat the disease in a less invasive manner, improving the quality of life of patients, as well as their chances for recovery. (RKI, 2017b) Despite this, in 2013, 71,640 women were diagnosed with breast cancer and, of these, 17,853 died from the disease, making it clear that the number of deaths due to breast cancer is still high in the country. (RKI 2017a; RKI, 2017b).

It must be noted that this research counted on the participation of Brazilian women who were younger than their German counterparts, since age was not a factor for inclusion or exclusion in the study. For inclusion, in both countries, the factors were time of diagnosis between 6 and 24 months, and cancer detected at a curable stage, at time of discovery. For exclusion, the factors opted for were pregnancy at time of diagnosis, as well as the existence of neurological or psychiatric problems prior to breast cancer, and women with these conditions were not interviewed. Among the Brazilians, 15 women participated in the interviews, with ages ranging from 35 to 65 years (with a simple average of 48 years at moment of diagnosis); among the Germans, 12 women were interviewed, with ages varying from 50 to 81 years (with a simple average of 64 years, which coincidentally fits within the data of the literature consulted in the country).

4.1 Comparing diagnosis discoveries

The discovery of a diagnosis occurred differently among the women of the two groups studied. For the Brazilians, most of the women noted the presence of a nodule or other breast alteration on their own, leading them to seek out a diagnosis. For most of the German women, on the other hand, attending a screening mammogram led them to discovery of the disease.

The Brazilians were subdivided into three groups, according to socioeconomic conditions: Group A - 4 (four) women with the highest conditions; Group B - 4 (four) women with intermediate socioeconomic conditions; and Group C - 7 (seven) women with the worst socioeconomic conditions of the group. With regard to obtaining a diagnosis, there were three distinct situations for the Brazilians that pointed to a connection between discovery of the disease and social conditions: 8 (eight) women identified an alteration in their breasts and sought out immediate medical assistance to ensure the possibility of a diagnosis (3 from group A, 3 from group B, and 2 from group C); 4 (four) women did not notice anything in their breasts and only began to consider the possibility of a diagnosis after a routine appointment at the gynecologist, who located the tumor and requested a mammogram (1 woman was from group A, 1 from group B, and 2 from group C); and 3 (three) women noticed something different in their breasts, but did not seek out specialized medical help, only doing so later, after being directed by people around to them (all in group C, the poorest in the study). Among the last, one woman sought help from a general practitioner, however, she stated that the professional did not request exams to verify cancer; this only took place almost a year later, when the woman went with her daughter to an appointment with a mastologist.

The German women were also divided into three groups according to socioeconomic conditions: Group K - 1 (one) woman with the highest conditions in the study; Group L - 7 (seven) women with intermediate socioeconomic conditions; and Group M - 4 (four) women with the worst socioeconomic conditions among the Germans. Regarding the discovery of a diagnosis, 6 (six) found out about the disease by means of a periodic screening mammogram, carried out at the invitation of the health insurance company (5 were participants from group L and one from group M). 2 (two) of the women discovered the disease by means of exams for verifying other health problems - one woman in group M had back pain, while the other, from group L, had surgery for shoulder issues. The remaining 4 (four) German women discovered the disease after noticing something in their breasts by themselves, leading them to see out immediate medical help (one of these participants was from group K, one from group L, and the other 2 from group M).

This data pointed to the importance of screening programs for an early detection of breast cancer, a technique adopted in many countries in Europe for over 20 years, corroborating with the findings of Bray and collaborators (2018). In Germany, where, according to RKI (2017b e 2020), women have been invited to do a mammogram every two years since 2005-2008 (depending on when each state of the federation joined the program), the results of the present study are in accordance with the literature, pointing to a higher number of diagnoses made by means of exams than self-discovery. In addition, these women receive less invasive treatment then Brazilian women. The situation among the Brazilian women was distinct, as none of the Brazilian participants discovered the disease through screening techniques, despite the existence of these in the country. When their doctors sent them for mammograms, they had already observed something in their breasts, leading to a referral for the exam.

Another relevant factor was the higher number of self-discoveries among the richer Brazilians, and, on the other hand, a higher difficulty among the poorer participants to obtain a diagnosis. This data reveals that money and information ease the path to a diagnosis in Brazil, while poverty and a lack of schooling increase the vulnerability of the population to serious diseases, such as cancer. In Germany, self-discovery of the disease took place for participants in each of the study groups, but especially for the older women, who are no longer covered by the screening programs, suggesting less vulnerability for the poorest social actors in that country, regarding breast cancer.

It should be noted that the self-discovery of the Brazilian women in group C can be explained by two factors, which are not associated to economic conditions. In Cristina's case, she had breast cancer in her family — her mother and maternal aunt had the disease before they reached 50 years of age. This had alarmed her, leaving her with the fear of a hereditary cancer, a possibility that a doctor had explained to her once while she was accompanying her sick mother. This led her to self-examine regularly, and she would periodically request mammograms from her gynecologist, due to being part of the risk group for the disease. In Carla's case, as she worked as a nurse technician, she learnt self-examination in her professional training and work, and practiced it regularly.

Another relevant factor in the study was that some of the Brazilian women, all from group C, waited a long time after noticing changes in their breasts. They took between 6 and 12 months, with breast pains, to seek out a diagnosis. Carolina thought that self-exams and gynecologist visits were women's practices, and thus were not relevant for her, a social actor that had assumed a male identity. Camila was afraid of doctors, and said that, *"At first, I knew nothing of what it was, I had no idea. Then I would tell my work colleagues that I was feeling a lot of pain. After everyone insisted, because I'm terrified of doctors, I decided to go and do some exams".* Camila's report reveals a lack of education and of enlightenment, besides a distancing between poorer people and medical professionals, since the fear of a doctor's appointment was not associated to any prior experience of this participant. She was asked: *"Camila, why did you say you are terrified of doctors? Has anything already happened with you involving a doctor or treatment?"* To this she answered, revealing her ideas on the subject: *"No, nothing has ever happened. My children were even born in hospital, in the hands of good doctors. My fear is because 'those who seek, find', and I didn't want any disease. So, I didn't think that the pain was enough of a motive to go to a doctor. (...)"* (Camila)

Finally, among the Brazilians it was noted that one woman from group C only found the disease because she had a mammogram for a plastic surgery that would involve her breasts and belly, which led to her doctor requesting this exam, among others. She reported her experience as follows: *"I went then, with this mammogram and other exams, to the plastic surgeon. It was a week before my surgery. And then the doctor looked at the exam and said like this: 'Madam, we are not going to do the plastic surgery now!' (...)"* (Cláudia) The participant explained that she couldn't imagine the reason for which she could no longer do her surgery, and it frightened her: *"I had a fright! Because she also said: 'What you have here in the mammogram is ugly, and we need to take care of it at once. I'm sending you to a mastologist, and you should take the result of the biopsy I am requesting here'."* (Cláudia)

Among the Germans, what stood out in the study was the speed of the diagnostic process. After the mammogram, in just a few days the women had their biopsy and, at the same time, their treatment recommendations, which for the most part began with surgical removal of the tumor. Only in 2 (two) of the cases there occurred a delay in obtaining a diagnosis. The first was Marlene, who believed that her pain came from her spine, and so went to her family doctor, who sent her for back exams. Because of these exam results, which showed a patch on her breast instead of back issues, the doctor sent her for a mammogram, which began the process of breast cancer diagnosis. In Loren's case, she took around three months to see a gynecologist, waiting passively for a new doctor to arrive at the clinic she was used to attending, all while suffering from strong pain in her breast and observing the physical deformity on the organ. During the interview, she was questioned about this: *"But you still felt these pains and no longer used the shoulder cushioning, why didn't you go to a different doctor instead of waiting for a new doctor to arrive at the clinic of your retired gynecologist?"* She responded: *"Because here where I live, in my region, you can't easily find a gynecologist. So, I waited at the place where I was already a patient, because certainly I would be a priority when the doctor was ready to work."* (Loren) It was not possible to verify the veracity of this difficulty in finding a gynecologist in the region, especially as some of the other women changed doctors after discovering their diagnosis, opting for outpatient care with a new gynecologist. This leads to the conclusion that perhaps Loren did not believe she had cancer, as she had a history of breast cysts for which she had already had biopsies in the past, and her results had not indicated cancer. Another hypothesis for her case is lack of information, something that was not confirmed in her reports. In counterpart, participant Karen had a mammogram just one day after finding a nodule on her own breast, leading her to immediately seek an appointment with her gynecologist.

Finally, among the German participants there was a greater prevalence of fear or anxiety when faced with the possibility of a breast cancer diagnosis. Liane, for instance, when receiving a phone call from the clinic where she had her mammogram, did not believe the exam had found something wrong with her breasts, to the point of thinking it might be a medical error. Louise and the remaining women, on the other hand, quickly went to the clinic, in fear that it might be breast cancer. Their reports contained a number of words associated to fear, such as: terror, horror, shock, fright, all relating to their mammogram results. This excerpt from Melinda's interview is an example: *"It's like a board to the head when you get the phone call. It's a horror! For the love of God, you have breast cancer, now what? Even you have to process it yourself, first." (...)* (Melinda) These results indicate that the screening technique, although effective, also leaves women apprehensive, with an exacerbated fear of the disease.

Participant Karen had a different reaction, compared to the other interviewed German and Brazilian women. She reported feeling embarrassed by the diagnosis, because she didn't think that women her age could have breast cancer. Karen justified her mistake by the fact that neither she, nor her friends of the same age, received the invitation for a mammogram after they turned 70. This led her to believe that breast cancer could not appear in older women. However, her prior professional training and experience had ensured that she was constantly aware of changes in her body, which led her to notice the nodule at an early stage. The other older participants, such as Matilda and Mia, also noticed themselves that something was different in their breasts, leading them to seek a diagnosis.

4.2 Discussing disease disclosure

Both among the Brazilians and the Germans, disclosure of the disease took place first with their spouses, with the women seeking in these partners an initial source of support in dealing with the disease. However, some of the Brazilians had no husband and so, initially, disclosure of the disease was made to other relatives, followed by friends. Of the German women, 2 (two) had husbands who could not be a source of support as they were ill and depended on care from their respective wives. These women, Matilda and Mia, had no support network besides that formed by the health care professionals who helped during their illness.

A different issue for the Brazilians was that two of them, despite having husbands who were healthy, could not count on them for support. This took place with one participant from group A, Aurora, and one from group B, Beatriz. According to her reports, Aurora's husband, who was already aggressive, became worse when she got sick, with verbal aggressions and threats against her while beating their children. In Beatriz's case, her husband distanced himself, rejecting her for the loss of hair and her surgery scar, introducing psychological aggression to their relationship by criticizing and censuring her for the changes in her body. Regarding these participants who had problems with their husbands, directly linked to the disease, it is worth noting Brazil's high rates of domestic violence, especially against women. Authors Guimarães and Pedroza (2015) connect domestic violence to the gender perspective, stating that Brazil's chauvinistic and patriarchal culture is responsible for legitimizing the several types of violence practiced by men against women. And, despite the Maria da Penha Law in effect in the country since 2006, there is still much to be overcome in order to change the everyday scenes of violence against women within Brazilian homes. Silva and collaborators (2010), by means of a qualitative study, concluded that men with a higher moral and affective structure tend to remain beside their mastectomized wives, and are more capable of supporting them than the men who do not have this structure.

Returning to support networks, adult children came next after spouses, appearing as important sources of support and trust for the women in the study both in Brazil and in Germany. However, some of the older German women did not have children, which was the case of Karen, Layla, and Mia. And even some of the older women with children, such as Melinda and Matilda, could not count on their help while facing cancer. Like the Brazilians, the younger German women, who were predominantly from group L, with one in group M, could count on their children, either to help in the house, accompany them to appointments and treatments, or others. An exception was Lisa, who complained of her children, saying that the fact that they were all men justified their lack of interest in their sick mother. She said she had needed and requested help, and also attention, as she felt more fragile and wanted them closer to her, however her requests were not fulfilled. It is interesting to note that she reaffirmed the conduct of her sons as characteristic of the behavior of "*boys*" (referring to their gender). This indicates that the participant had accepted and incorporated in her speech a separation of gender roles, something she may have transmitted to her children. Lisa's posture diverged from the other German women, who did not define directly which roles would belong to sons, daughters, daughters-in-law, or sons-in-law, in terms of the help offered to the women during illness.

Joan Scott (1990) brings the gender debate to the academic sphere, referring to the impossibility of looking at social constructions without paying careful attention to the relational dimension of the masculine and the feminine, beyond the simple logical binary of the sexes. Judith Butler (2003; 2015a; 2015b) and Heleieth Saffioti (2004), among others, agree with the studies of Scott (1990) stating, for example, that the area of gender pertains to women, children, families, and ideologies, but also needs to take into account diplomacy and high politics, otherwise it will sustain the dichotomy between men/women, sexuality/politics, family/nation. Melo (2008) reflects that the woman at home, caring for her chores, is socially within her natural domain; however, this naturalization of a woman's roles stems from the historical construction of patriarchal societies. What happened to Lisa and also Matilda, who didn't even receive visits from their children while sick, suggests there is still something of the patriarchy that brings harm to the lives of some of the German women.

Among the Brazilians, there were families with children still at home — either children, adolescents, or young adults who were not yet able to live on their own. Two of the women, both from group C, also had grandchildren living with them. The German women all lived alone with their spouses, while children and grandchildren were just visitors in their homes. In any case, the disease appears to have functioned, for most of the women in the study, as a driving force for a reshuffling of roles and functions within the families, with many children taking on duties that had belonged to their mothers, such as household chores. In some cases, the children also helped financially, as took place with Camila, Cláudia, and Clarisse, some of the poorest Brazilian women in the study.

One aspect that showed plenty of diversity was the composition of the rest of the women's support networks. For the Brazilians, after diagnosis was confirmed, this network expanded to include sisters, then friends, and finally other relatives or even neighbors. For the German women, this support network was almost exclusively made up of spouses, sons/daughters, and sons/daughters-in-law, and did not expand at any moment during their fight against cancer. These results suggest that cultural differences between the countries also created differences in facing the disease, changing greatly the characteristics of the support networks.

This topic includes the theme of non-disclosure and also late disclosure of the diagnosis. Some of the Brazilians, from all groups, kept the news at first from certain people, for instance, elderly or sick parents, young or adolescent children, work colleagues, and a few specific relatives. They waited for the moment they judged most appropriate to then reveal the news. However, at the time of the interview, all had told their nuclear families and other relatives of their illness. Only one participant, Bruna, still tried to hide her illness from her neighbors, especially the most elderly ones, who would have shared pessimistic outlooks for her cancer prognosis.

Among the Germans, news of the diagnoses remained predominantly within nuclear families, and was not shared spontaneously with other relatives or acquaintances. Some of the German women, all from group M, believed their neighbors and more distant relatives already knew that they were ill, but this did not bother them. As Matilda said: *"(...) 'What else is left for you besides going through this?' — I thought, and believe it is what the others* (neighbors and relatives) *think! If that is what they think, why don't they show up here to help. But they do know, that I'm ill."* For Marlene, a woman who would go through chemotherapy, revealing the disease was a choice she made, opting to tell all of her acquaintances that she had cancer, and that she would be facing the side effects of chemotherapy. She chose not to feel embarrassed about this, since she knew she would lose her hair and spend a while looking different.

Karen and Mia, on the other hand, felt obliged to disclose their illness because they were questioned by friends who wanted to know why they had disappeared from their social circle. Under these circumstances, telling the truth about breast cancer was the best option. Karen was more comfortable with this, and soon went back to spending time with her friends. Mia was not so comfortable with the situation, and opted for distance from her friends, only speaking to them over the phone. Comparing the reports of the German women, it was possible to observe that the higher the level of education, the bigger the effort to hide the diagnosis from people who had no close family ties. This suggests that this phenomenon may be directly associated to the conduct of the interviewees, who drew rigid lines in their lives in terms of which subjects were of public or private domain, as discussed in item 3.6.1. These postures can be seen in the words of Mia and Liane. For Mia, not speaking to her friends, and restricting what she would say to her two friends who had already gone through breast cancer, was a way of avoiding building up her fears about the disease. As she said: *"(...) And you don't necessarily need to pass that along. It's a matter of posture! We are not the type to talk unnecessarily. (...)"* (Mia) For Liane, the lines drawn between what she would and would not talk about did not apply only to acquaintances, for whom she would like to maintain a healthy image. She also mentioned restricting what she told her children, so as to spare them from suffering, and even watching what she told her husband, who couldn't always help her when her conflicts were internal. The results of the study point to this being a socially constructed practice, transmitted between mothers and daughters in the society these women were inserted in. They also indicate that this factor is associated to the difficulty these women had in accepting help from Psychology professionals during treatment.

4.3 Debating the treatments and their implications

The literature on breast cancer treatments discusses from epidemiological data, showing the relevance of screening for early diagnosis allowing less invasive treatments (RKI, 2017b, Bray et al, 2018), to medical options for chemotherapy or radiotherapy as adjuvant or neoadjuvant in controlling the disease. (Youlden et al., 2012; Maluf, Buzaid & Varella, 2014; RKI, 2017b). At the same time, many authors debate the side effects of breast cancer treatments, suggesting conducts to minimize the impact of these on the lives of sick women. (Ashing-Giwa et al., 2004; Porter et al. 2009; Panobianco et al., 2014; Fayer, Guerra & Cintra, 2016; Kozir, 2018)

To receive treatment for breast cancer, the women resorted to different kinds of health insurance. Of the 15 (fifteen) Brazilian participants, 6 (six) women underwent all of their treatment within the Brazilian public health network, SUS, which had no direct cost to them. Most of these women were in group C with only one from group B. 3 (three) of the women were treated by means of the IPSEMG network, with 2 (two) of these belonging to group A and one to group B. Finally, 6 (six) women resorted to private health care networks for their treatment, using different insurance providers. Among them were 2 (two) women from group A, 2 (two) from group B, and 2 (two) from group C.

Although free access to health care services is a right of all, guaranteed by the Brazilian constitution, the reality is that, according to research data, many people, even those who are poor, turn to the country's private insurance companies. Participant Cláudia clarified what many Brazilians might think, saying: *"My children have paid UNIMED for me for years. They know I am elderly, and if I had something, they don't want to see me die in line for SUS. As in fact happened, that now I do treatments for cancer through my insurance, thanks to them.* (children)." (Cláudia). SUS, the Unified Health System, is responsible for offering comprehensive healthcare to the Brazilian population; the institution has advanced in many ways since its implementation in the 1990s, but still suffers from a number of issues such as budget cuts and political interest conflicts, besides being threatened by private capital, which leads to a mistrust on behalf of part of the population. (Paim, 2018; Duarte, Eble & Garcia, 2018) The results of the research align with the mentioned authors, as even the poor women in the study migrated to private health insurance companies.

In Germany, only the participant from group K had private health insurance, while all the other women had State insurance, which covered their treatment. The data found in the research suggests agreement with the Das Gesundheitssystem kennen lernen (2015), which explains how health services in the country work. According to this document, around 90% of the population is linked to a State insurance, while 5% of Germans have private insurance, 2% have other types of insurance, and 3% have nothing, despite affiliation to GKV being mandatory in the country.

The Brazilian women interviewed went through different surgeries that, according to the medical literature consulted, are procedures considered as definitive treatments for breast cancer. (Maluf, Buzid & Varella, 2014; Panobianco et al., 2014). Three women, Camila, Bianca, and Brigite, went through radical mastectomies, which is the complete removal of the breast, including areola and nipple. However, only Bianca had breast reconstruction, covered by IPSEMG; the others were awaiting this, which could be offered later by SUS. INCA (2019) affirms that women who go through mastectomy have a guaranteed right to breast reconstruction, either by SUS or by private health plans, when women have these. As for the remaining women, 7 (seven) had partial surgeries, such as quadrantectomies, while others, such as Ana, Carolina, and Cristina, were undergoing neoadjuvant chemotherapy and already had their surgeries booked. Antônia and Carla, who were also undergoing neoadjuvant chemotherapy, had not yet been referred to surgery as part of their treatments; they did not know the reason for this, nor was it clear in their medical records.

All the Brazilians, without exception, were submitted to chemotherapy, receiving this treatment in two stages; one of these stages, which they named *"the red"*, usually lasted 4 sessions, while the other, that they called *"the white",* had on average 12 sessions. *"Red chemotherapy became known by this name among patients due to its reddish coloring. These are medications from the group of anthracyclines, called doxorubicin and epirubicin."* (Wecare, 2018, p.1) The white chemotherapies are a different sort of medication, which according to Wecare (2018,p.1): *"includes all medication that is not part of red chemotherapy, and has no coloring, being completely transparent. Among them are substances called taxanes, which are docetaxel and paclitaxel, among other medications*."

Only one participant in the study, Bruna, was undergoing a second cycle of this treatment, in other words, she had already completed the two previous stages of chemotherapy, but since the tumor had not responded well, she was going through treatment again, although with different medication. In her words: *“(...) Because in a new biopsy, done on the lymph nodes 2 months ago, the doctors identified a new contamination, or something like that. And that is why I’m having to go through a second cycle of chemotherapies, now with other medication. (...)”* (Bruna) As for radiotherapy, only 2 of the Brazilian participants were prescribed this treatment, Aline and Cláudia. And seven of the interviewees were undergoing hormone therapy. There were not as many complaints about these treatments as there were for chemotherapy.

The German participants received slightly different prescriptions for breast cancer treatment, compared to the Brazilian women. In Germany, all of the interviewees went through radiotherapy. However, only three, Loren, Marlene, and Matilda, received chemotherapy. One woman, Layla, was also prescribed chemotherapy; however, she refused this treatment. All the women underwent surgery, predominantly quadrantectomy. Marlene was the only one who had a mastectomy. And last, eight women were receiving hormone therapy.

These differences in the treatments received by the two sets of research participants were relevant for result analysis, since, according to the women, chemotherapy brought more side effects than the other forms of treatment. Some of the adverse reactions mentioned in the reports included loss of hair, loss of body hair (such as eyebrows and eyelashes), and in some cases, frequent vomiting and diarrhea, and mood swings, besides weight gain or loss and excessive fatigue. These reports confirm information in the existing literature, which points to chemotherapy as the breast cancer treatment capable of causing most side effects, as suggested by Maluf, Buzaid, and Varella (2014) and INCA (2001; 2019).

Chemotherapy earned an exclusive subchapter, both when analyzing the Brazilian experiences, and that of the German women. For the Brazilians, the treatment was seen as extremely invasive; *“Chemotherapy was a tsunami for me”,* affirmed participant Carla. She compared her experience in receiving chemotherapy to being swept away by a tsunami; a similar opinion to that of the other women, who also reported feeling devastated by the side effects of this treatment. For most of the Brazilians, chemotherapy brought a great quantity of changes in their organisms, from physical to psychological and/or emotional, demanding they fight hard in order to survive the disease. Aline stated that if she kept thinking about it, she would have already gone mad: *“(...) When I looked at myself in the mirror and saw that* *figure, which didn't represent me at all, I would get terrified. So, I opted to give myself time, and avoid thinking about all the side effects of chemotherapy, because I didn't want to go mad."* (Aline). Carolina acted in a different manner, stating that chemotherapy made her feel crazy: *"The sensation is that chemotherapy brings all sorts of junk into your body. I don't know... You don't feel well! You go crazy, crazy, crazy, crazy, but then you have to try and control yourself. (...)"* (Carolina)

For Charmaz (1995), many sick people believe in their own internal strength, while sensing their bodies fall apart. Accordingly, they give up total control over their bodies, making changes in their identity so that their self can adapt to the new conditions of their body. But although they cede control of their bodies, they seek to control themselves by relinquishing or lowering their identity goals. The author also clarifies that sick people, for the most part, understand when to fight and when to surrender. Thus, they end up becoming impervious to social significance, or begin to devalue this significance, which otherwise might not help them with the disease.

The subchapter discussing chemotherapy among the German women was titled "*A sigh of relief: 'freedom' from chemotherapy"* because, although three participants underwent the treatment, another nine did not, and considered this a good thing. The eight women who were not prescribed chemotherapy, besides speaking of their own relief, also reported that their doctors indicated this was a good sign. Liane mentioned that not just her, but her entire family were satisfied with the news that this treatment would not be necessary: *"(...) My children were around me daily, and so was my husband. And there, when we found out it would be just radiotherapy, we all made the sign of the cross. It was a grace we received from God, so we gave thanks."* (Liane) Melinda added her doctor's comment on the subject: *"He* (the doctor) *came down the hallway and said: 'Mrs. X, you can open a bottle of wine or champagne today! Because for you, it's like winning the lottery. You don't need chemotherapy.' That was really great, I also got excited."* (Melinda) Similar to Melinda's experience, Louise, Ludmilla, Lisa, and Larissa also heard positive comments from their doctors, for not having cancer at a stage that would demand chemotherapy treatment. However, even though the majority of interviewees did not go through chemotherapy, they had a number of complaints associated to the other treatments, such as post-surgical pain, radiotherapy burns on their skin, and fatigue and excessive tiredness, associated both to hormone therapy and radiotherapy.

An unforeseen situation occurred with Layla, who did not accept chemotherapy, having opted personally to refuse the prescribed medical treatment. For her, *"(...)*

chemotherapy, didn't knock me off my track", meaning that she did not lose control of herself, as she had seen happen with others who underwent this treatment. She said, *"(...) that person either would die very quickly or be very ill, completely out of it"*, using this to explain what she had observed in her friends and some of her patients in the past (she was a professional esthetician) who underwent chemotherapy.

Layla's decision brought her problems, not just with some of her doctors, but also with the health insurance that was covering her treatments. She ended up having to pay privately for some of her medication, as well as for some of her radiotherapy, as her insurance had been notified that she needed chemotherapy but had refused. Therefore, her insurance stated they would not cover her other breast cancer treatments, since they were interdependent. Layla remained firm in her choice and was thus obliged to send a medical report to the health insurance company to justify her need for the other treatments, otherwise she was at risk of dying. After this, the state health insurance she subscribed to, agreed to cover her other treatments and procedures.

Rehabilitation was a subject that didn't come up for the Brazilians, since this type of breast cancer treatment has not been adopted in the country. However, some of the Brazilians commented briefly on lymph node drainage or physiotherapy, since after surgery they had not regained full movement in their arms. Aline, Bianca, Beatriz, and Cássia all went through physiotherapy in order to improve movement in their arms and shoulders. Psychological support was also mentioned by some of the Brazilian women, two of which were referred to a psychologist at an NGO due to anxiety regarding chemotherapy. Another four women already used, or went back to using, psychology services, finding that this type of support gave them strength to deal with treatment, according to their reports.

In Germany, on the other hand, the subject of rehabilitation — known as *Reha* — was brought up by all the women. Some were referred to and went through this treatment. Others, despite receiving a referral, did not wish to go through the rehabilitation process. And there were also those who did not receive a referral, but knew of and spoke about the subject. According to the Deutsches Krebsforschungszentrum (2018), rehabilitation in the country is divided into three types. The first is the post-surgical monitoring, known by healthcare professionals as primary rehabilitation, which occurs while the patient is still in hospital and generally applies to all women, according to their immediate demands. Follow-up rehabilitation takes place during subsequent stages of treatment, such as radiotherapy or chemotherapy, when individual measures are prescribed to each patient, according to recovery demands. This type of rehabilitation may include physiotherapy, occupational therapy, and psychology, as outpatient processes. The third type of *Reha* is carried out within a specialized cancer rehabilitation center. This form of support is more focused on cure or general rehabilitation and is an inpatient process that lasts on average three weeks. Loren, Liane, Lisa, and Marlene went through this last type of rehabilitation, with hospitalization *"for cure",* as they said. Participants Larissa, Louise, Ludmilla, Matilda, and Melinda were not prescribed inpatient *Reha,* while Karen, Layla, and Mia did have a referral for a rehabilitation center but opted not to attend.

The Deutsches Krebsforschungszentrum (2018) also states that the German federal pension system (*DRV Bund)* has compiled specific standards for rehabilitation therapy of patients with breast cancer in the country, with guidelines to be followed by all inpatient clinics that specialize in *Reha.* Thus, treatment must contain a series of items, listed in subchapter 3.5.3, that include: information about the disease; sports; lymphedema treatments; psychological counseling and psychotherapy; and assistance in applying for benefits and support measures for the patient's professional and social integration. The wider aim of this type of *Reha* is a faster recovery of the patient, especially those who must return to work.

4.4 Debating fear

In general, discourse on fear, associated to moments of treatment, was more prevalent among the Brazilian participants than the German women. One reason for this may be found in chemotherapy side effects, since all the Brazilians had been through or were receiving this treatment at the time of their interviews. For the most part, they were living under severe dietary restrictions, and suffering from hair loss, fatigue, or exhaustion. This physical exhaustion could be noted, in a minority, not just in their reports but in their difficulty in speaking, requiring frequent breaks to catch their breath. Another explanation for the phenomenon was the more communicative stance adopted by the Brazilian participants, with less boundaries between the content that belonged to the public or the private sphere. They did not appear to have resorted to camouflage or restrictions regarding the themes of fear of recurrence or even fear of death.

Important variations were also observed among the Brazilians regarding the manner in which they dealt with the fears brought by others to their daily life, and that were associated to the social stigma of the disease. Most of the women adopted a defensive posture and were critical when others suggested they were condemned to die from breast cancer. As Aline said: *"(...) Because people think that everyone who has breast cancer is going to die, and if I go* *with her ideas, I'll feel obliged to die, but I have no such obligation."* However, a minority of the women reported suffering from the comments of others, and becoming embarrassed by them, such as happened with Bruna: *"(...) A neighbor who was almost ninety years old came to me and said: 'X who had the disease died, I'm afraid of this disease because it kills!' (...) 'I'm going to die too, right!?' And thinking of that made me feel terrible."*

For the German women, fears were discussed with more reticence, and only a few of them spoke openly of the fear of recurrence, while a minority mentioned a fear of death. Their biggest fears surfaced when they talked about the moment when they were called in by the clinics where they did their mammograms, and they first experienced the notion that something might be wrong, along with the possibility of the disease. The stigma of cancer was very present for the majority of women, whose reports included words such as "fear", "horror", and "shock" when referring to the idea that they might be facing a cancer diagnosis. In the words of Liane, used to represent the thoughts of the majority: *"I was terrified, I had a shocking fear. So they sent me to the hospital the next day, to remove the sick tissue, or in other words, a perforation, as they called it. I wasn't myself anymore. I didn't know myself anymore, all I did was shake and cry. (...)"* (Liane)

The German women also mentioned a great fear of the biopsy results, or the results from examination of the material removed in surgery, which would indicate the type of treatment they would receive. All, without exception, feared having to go through chemotherapy, as previously discussed. In Mia's words: *"So, after the smear test they did in Augsburg, I went home feeling insecure. Everything seemed to indicate a cancer, but I still had to find out if it was a cancer that would need chemotherapy. Of that treatment, I admit I am afraid."* (Mia)

Some situations stood out, in relation to the aforementioned fears, once treatment was defined, such as in Liane's case, who affirmed several times that *"I am not afraid of death, I never was"*, directing her fears instead to the dread of suffering uncontrollable physical pain or becoming dependent of the care of others. However, she was the one who introduced the fear of death to the interview, which suggests she might have been trying to convince herself that she was not afraid. Other participants — Lisa, Louise, and Ludmilla — spoke openly of their fear of dying, or of cancer recurrence, setting them apart from the other German women. An excerpt from Louise's interview exemplifies the fear of these women: *"I will never be the same again. I will always be afraid that this disease might return. Besides the fear of not discovering something in time for a cure. (...) I'm afraid of dying! I don't know, it's a fear that crosses the thoughts of women going through this disease."* (Louise)

Finally, there were also women who noted this fear of death in their treatment colleagues, but not in themselves, as in the case of Loren, who went through chemotherapy. Marlene, who also received this treatment, did not speak about the fear of dying, but of the fear that her daughter-in-law would die from the disease, as she was young and had small children.

4.5 Dealing with oneself during illness

The discovery of cancer brought shock, or a moment of great apprehension, to all the interviewees from both publics in the study. Initially, the women sought to assimilate what was happening to them and how they could handle it, all while submitting to the first prescribed treatments. Next, they had to find new forms of managing their bodily experiences, often replete with physical discomfort, due for the most part to treatment side-effects. In one case only — that of German participant Matilda — the woman was observed to have limited herself, as she neglected her physical suffering and maintained an unaltered routine, even while dealing with her own illness.

During the treatment stages, most of the Brazilian women were concerned about maintaining the output of their distinct social roles, whether as mother, wife, and in some cases, as professionals, since the majority was on medical leave at the time of the interview. To remain socially inserted, the Brazilians fought to adjust their different subjective experiences to their new corporeal experiences after suffering physical changes due to chemotherapy. Of the Germans, who also carried out social roles as mothers, grandmothers, and wives, 6 (six) women were already retired, and free of their professional roles. However, among the other ones who had yet to retire, 3 (three) were already back at work at the time of the interview, and therefore had to deal with their job-related roles as well.

The words of one of the Brazilian participants, Ana, stands out among the results, when she stated that cancer brought a radical life change: *“So it* (cancer) *is not just a disease, because treating it is not just about taking the medicine, or doing chemotherapy, surgery, radiotherapy, you know, it’s an issue that really affects human beings, that brings a radical change of life.”* (Ana) This helped understand the reports of all interviewees, who for the most part underwent life changes after becoming ill. Thus, it was possible to catalogue situations of intense change associated with the process, especially among the Brazilians in the study; these include one woman’s pregnancy and the beginning of divorce for two others. Besides a strict dietary discipline, growing ill demanded control over physical activities, more self-care with different newly sensitive body parts, and also a daily dedication in the search for clothing and accessories so that the women could continue their routines, since they had lost hair, gained or lost weight, and so forth.

For the Germans, the key challenges in their routines revolved around managing the excessive fatigue. However, radiotherapy also demanded more skin care, in terms of hydration, and also required attention to diet, which needed more fiber due to constipation caused by the treatment. A few interviewees also mentioned some physical discomfort which, according to them, was linked to hormone therapy. This included waves of heat, bone pains, or insomnia.

Dietary discipline, among the Brazilians, proved a reason for some of them to move away from activities that had formerly brought them pleasure, such as cooking for their families or frequenting parties or other social gatherings involving food and drink; this favored the enforcement of a partial social isolation. Due to chemotherapy, their diets had to be under constant vigilance, and food that was greasy, overly processed, or fried, among others, was to be avoided. At the same time, their diets should be enriched with vegetable soups, fresh fruit juices, and fiber rich food. Many of the women also suffered from continuous nausea, reporting difficulty eating in the period when they were undergoing chemotherapy. In addition, a significant number of the interviewees were poor (the women in group C), and this brought difficulties in accessing the food they needed, such as meat, yoghurt, fruit, and vegetables; items that had not been part of their dietary routine. In this manner, some of the women had to count on support from relatives and/or NGOs in order to be able to afford a more balanced diet during chemotherapy.

Among the Germans, it was noted that a healthier diet, with less fat or industrialized products, was already a habit for women in all groups, even among the poorest of them. Some even grew their own vegetables. These women had distinct concepts regarding health, which included dietary habits, the regular practice of physical activity such as walks, leisure, and the habit of avoiding vices such as smoking, alcohol, or drugs, as mentioned in their reports. A few also mentioned opting for organically cultivated produce (which they called “*Bio*”) and homeopathic medications or products. These discussions did not appear as frequently in the reports of the Brazilian participants. Some of the Germans also mentioned the search for vitamin complements, having complained that their health insurance did not cover that sort of medication, as can be seen in Mia’s words: *“This illness is very expensive! The health insurance does not pay for vitamins and does not care if we have money to buy this medication. We are elderly and we need this. It’s a paradox!*” (Mia) Others, such as Lisa, criticized the possibility of a completely nutritious diet, mentioning time and money as limiting factors: *“Choosing food and being able to buy everything right, to have a good daily nutrition, costs money and demands time. ‘Quatsch!’* (ridiculous!) *Of course, a vitamin complement is important and helps with cancer. But the health insurance won’t pay for it.*” (Lisa)

Some of the Brazilians were told by their doctors to take up walking, so as not to be too sedentary and to improve their overall health conditions by physical exercise. However, most did not like this, refusing to go for walks, Others followed their doctors’ orders, but complained that exhaustion left them limited. Only one, who was already a sports enthusiast, had no issues with this. Aline, the only women to practice sports regularly, had to moderate her rhythm with the disease and restrict her running and swimming habits, adapting to walks. Carla, on the other hand, only enjoyed going out to dance occasionally, and when she became ill, she did not accept her doctor’s recommendation of walks: *“I can’t even walk a few blocks, because I feel weak. I used to like going out dancing, but that was to have fun. (...) How can my doctor tell me to go for walks and have a normal life?! Normal how?”* (Carla). For Brigite, walking was a waste of time: *“(...) The doctor told me to walk, to improve my well-being. But for me this is a waste of time, because I already do many things here, such as laundry, ironing, and cleaning the house. I don’t need walks.”* (Brigite) It must be pointed out, however, that 5 (five) of the Brazilian interviewees did not mention carrying out regular physical activities, either on their own, or by medical recommendation.

On the other hand, the regular practice of some form of physical activity, especially walking, was mentioned in all of the German interviews, making them stand apart from the Brazilians in this aspect. The matter was discussed in a specific subchapter within the analysis of the German results, as it deserved special attention among groups L, M, and K. Another difference was that Liane and Karen spoke of vanity and made a connection between caring for their physical appearance and the practice of physical or sporting activities. The other German interviewees mentioned: walks — adopted by 8 (eight) women even before the disease; biking — carried out by 6 (six) women; or frequenting a gym — 4 (four) women practiced bodybuilding before cancer. For the majority, different from Liane and Karen, the practice of physical exercise was legitimized in their reports as habits that had been adopted exclusively for health benefits. And nearly all of them stated they still exercised, especially with walks in the fresh air, as a resource for physical conditioning and general well-being.

4.5.1 Discussing adaptation and identity goals

Charmaz (1995) seeks to explain how body, identity, and self are interconnect during prolonged illness, or in the life of someone with chronic illness. The author introduces a process she named adaptation, which is a lifestyle that the sick person adopts in order to deal with bodily functions that have been compromised or lost due to disease. The author's concept of adaptation encompasses alterations in the lives of those who become ill, with the intent of accommodating the self to the physical losses, and so promote an integration between them — body and self. For this adaptation to take place, it is necessary for the sick person to recognize their limitations or incapacities and make changes in their life and their self in a manner that allows them well-being, while still remaining socially integrated. In the words of the author: *"The corporeal limits and the social circumstances generally 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 the disease."* (Charmaz, 1995, p. 657)

Regarding identity goals, Charmaz (2009), referring to a previous work of hers - Charmaz, 1987 - clarifies that these stem from the intentions, the desires, the idealizations, and the behaviors that people adopt. For some people, identity goals are implicit, and cannot be described or declared in words since they do not comprehend them. Others have explicit identity goals that they have assimilated well, being able to speak about them skillfully. Thus, identity goals, in the perception of the author, are the preferred identities of an individual at a specific moment, and these can change according to the life experiences and circumstances of that individual.

Within the concept delineated by Charmaz (2009), there is a hierarchy of identities, which the author described in her 1987 work, and which people define when setting forth ambitions for their own lives. However, people who are ill tend to seek a reduction in their identity goals in order to better integrate their self with their sick body. In the hierarchy of identities of people with chronic illness, the author catalogued: Above Average Social Identity — which demands from the individual acts that are distinct from the rest in conventional life, even if they are sick; Reestablished Identity — a return to what they were before illness, reached through improvement in physical conditions; Contingent Personal Identity — which is uncertain, and may or not be possible, as it depends on contingencies, and may be compromised by the intercession of the new disease; and Protected Identity — which conserves ideas about themselves, as well as prior ambitions, based on the activities or physical attributes experienced before the disease. The location of the self in the hierarchy of identities alone does not predict the person's success or failure in the fight against illness.

In *Good Days, bad days: the self in chronic illness and time,* Charmaz (1997) concludes that the effects of disease upon the self vary between loss and transcendence. And that sick people can experience better or worse days, not just due to the course of the disease and its related adversities, but in terms of what they manage to extract from their daily experiences with this. Feelings may be more or less positive, based on how sick people manage to adjust their own self, and their identity goals, to their sick bodies. When a loss of self takes place, this means the person was involuntarily stripped of their former attributes and feelings, with which their concept of self had been constructed. And that they remain permanently unsettled, without being able to respond to the actions and experiences upon which their self was based, as they cling mainly to their losses. This makes their self vulnerable to the humiliating images mirrored by others, resulting in passivity.

However, what happens to most sick people is a transcendence of the self, that does not remain attached to loss. Thus, the disease does not fill or flood the self, even though it might fill or flood the experience of the sick person. Charmaz (1997) explains that transcendence involves self-acceptance, instead of simply any acceptance of the disease, which may be wrapped in stigmatized images and expectations of resignation. For the author, transcendence implies a reevaluation of life goals, and renewal based on this. For the sick person to reach transcendence, they must make choices and act so as to gain autonomy over their choices. In addition, loss and transcendence take place at different moments of time spent with the disease, reflecting their meanings in the day-to-day of the person going through chronic illness. The author also concludes that some people will not be capable of experiencing transcendence, being more involved in loss, and this may lead them to succumb to the disease. There are also those who have more limited choices, as they may have more issues relating to a lack of social support, or even a lack of medical or financial resources to deal with disease.

Returning to the results of the study, among the Brazilians, there were many women undergoing processes of intense suffering, due to the physical and/or psychological aspects — experienced as loss — that were associated mainly to the side effects of chemotherapy treatment. Some of the women appeared to have reached a transcendence of their self, at least in some aspects; others had not, and their focus was still on the losses suffered and the damage caused by this. However, the key difference between them was how this suffering was managed, and how they dealt with adaptation to the disease, with a reduction of identity goals and/or self-acceptance. Also, some of the women who experienced self-acceptance found themselves making use of their losses to place them in a position of mastery regarding the disease; a situation that was noted among the women who had above average identity goals. At the time of the interviews, the Brazilians were not yet completely free from their treatments, therefore none had experienced a **reestablished identity goal.**

Some women, most of whom were in group A, demonstrated that they were dealing with their suffering by means of an **above average social identity goal**, as in the case of Ana, Aline, Antônia, and Bianca. Others shared reports that led to a recognition of a **contingent identity goal**, including Aurora, Beatriz, Camila, Cássia, and Clarisse. Finally, Bruna, Brigite, Carla, Cláudia, Carolina, and Cristina were all identified as living with a **protected identity goal**.

For the German women, it could also be noted that some of the positionings adopted brought a transcendence from suffering while they adjusted their identity goals, adapting self and body; or even by maintaining prior identity goals, but with self-acceptance. Some of the women, without changing their identity goals, simply reduced their daily life goals; for example, by minimizing the pressure of household chores, recognizing they were weakened by the disease. However, there were also women who remained immersed in loss, without much conviction that they would overcome it. These last had a higher tendency to succumb to the disease. There was only one case where a posture was observed that revealed a denial or belittling adopted by the woman, regarding the adversity of the effects of the disease and its treatments upon the body and upon her integrity.

Among the Germans, at the time of the interview, Karen, Layla, and Mia were observed to have an **above average identity goal**. Participant Larissa revealed a **reestablished identity goal**; and a **contingent identity goal** could be identified in Loren, Louise, and Ludmilla. Finally, with a **protected identity goal,** were the majority of the participants: Liane, who had reduced significantly her identity goals after living with the disease; as well as Lisa, Matilda, Marlene, and Melinda. Comparisons between the positionings of the women in both countries will take place in the next subchapter.

4.5.2 Marking differences in positioning

Analysis of the reports of Antônia and the Brazilian women mentioned as facing illness by means of an **above average social identity goal** led to the conclusion that not only did they deal well with suffering, having gone through transcendence while, for example, losing their hair or putting on weight, but they also attempted to transmit their ideas to other treatment colleagues, as if adopting a position of mastery in face of the disease. Among these were two of the founders of a formal support network. This is described in item 2.5.3, “Strengthening yourself, strengthening others”, which discusses the importance of mutual social support for women with breast cancer, verified among the women interviewed.

Not all the German women with an **above average social identity goal** appeared to be successful in facing the disease. Karen and Mia mentioned lowering many of their goals, such as daily care for the house, the dishes, or the garden; in this manner, they dealt better with suffering than Layla. Participant Mia’s words even contributed to the subchapter title: *"The dishes and the house can wait for rainy weather to be cleaned".* Another thing they did was give into their daily fatigue, allowing themselves to nap on the sofa. Layla, on the other hand, stated that she suffered with everything that stemmed from the disease, especially nighttime insomnia and daytime sleepiness. This daytime fatigue made her furious and angry at herself. Although Layla had been forceful in not accepting chemotherapy, as she thought it would harm her more than it would help, by the time of the interview, she appeared to have succumbed to suffering, holding onto the physical and psychological losses that came with illness. For this participant, everything was a reason to feel bad about herself, such as the post-surgical pain, the antibiotics she took for infection, and the daily fatigue that she did not know how to manage.

There was, however, a single participant in both countries with a **reestablished identity goal,** Larissa. This participant no longer needed treatment, as she had finished her radiotherapy sessions a few weeks before the interview, and her cancer did not require hormone therapy. On the occasion of the interview, facing the disease consisted in undergoing periodic exams every three months. Analysis of her reports pointed to a transcendence of suffering, from the moment when she was still in radiotherapy. Larissa had hopes for a cure of the disease and was planning on enjoying her long-awaited retirement once she was cleared from further radiotherapy. She mentioned that support from her children was very important for her, especially in post-surgery, when they helped her with drainage and cared for her home. The participant said she was already recovered and enjoying the present moment, and that she and her husband were planning a schedule for the trips they would soon undertake. However, she affirmed that she would not under any circumstances miss her check-ups: *“(...) I am cured. I have nothing, no symptom that still harms me, and I feel recovered. But of course, I won’t miss any of the check-ups!* (Larissa)

As for the women who identified with a **contingent identity goal**, and starting the discussion with the Brazilians, they varied between ease and difficulty in dealing with hair loss and the other changes in their bodies. Beatriz, for example, went through transcendence when she saw her new hair begin to grow, which gave her hope. It was at this moment that she took the decision to divorce her husband, who had not supported her during her illness, and instead had rejected and embarrassed her. Camila and Aurora, who never lost hope, were women who found in their love for their children a reason to transcend from their suffering. In Aurora's case, her children motivated her to file for divorce, since her husband had begun beating them when she got sick. For Camila, the love she observed within her family, *"even having children from different partners"* (her words) and not having daily contact with all of them (children), was a reason for pride and appreciation of her own existence. In this group, two women stood apart, Clarisse and Cássia, both of whom appeared to be succumbing to the disease.

Clarisse's problems began with the conflict between what her neighbor told her, of the risk that she could have cancer, and what her first consulted doctor told her multiple times — that she did not have the disease. From this moment on, noting that she felt more and more pain in her breasts, she began taking anxiety medication, prescribed by the doctor, mixing it with alcohol. Clarisse was immersed in the fear of death, which in her mind could take place if she had breast cancer. Her suffering grew with confirmation of her diagnosis and was worsened by her hair loss, after her first chemotherapy sessions. Cássia's case was different from the other interviewees as she went through pregnancy during her treatments, becoming pregnant after stopping her contraception on her doctor's orders. She appeared to be completely submissive to medical discourse, developing a fear of having delayed chemotherapy due to pregnancy and, consequently, believing she ran a higher risk of dying from cancer. As she said, *"life became a 'what if?', one question after another, without much hope of positive answers."* (Cássia)

At this point it is worth noting that what the doctor says, or leaves unsaid, influences greatly a patient's discourse. As stated by Foucault (2005a), there are striking differences between the discourse of the doctor and of the sick person. In his words: *"[the] status of the doctor entails criteria of competence and knowledge; institutions, systems, pedagogic norms; legal conditions that give the right — not without first fixing limits — to practice and the experimentation of knowledge."* (Foucault, 2005a, p. 56). Foucault also mentions that *"even though discourse may apparently be a small thing, the interdictions that reach it soon reveal, rapidly, its connections with desire and power."* (Foucault, 2005b, p. 10) Research indicates that Clarisse and Cássia’s issues with the disease were aggravated by their passivity when faced with the imperative of medical discourse.

Among the German women identified with a **contingent identity goal,** all appeared to be immersed in suffering, which didn’t indicate that they would succumb to the disease. For example, Loren showed a great passivity in face of medical discourse, especially with regard to the professionals she already knew, since she waited around 3 months with pain and the visual perception that her breast had become deformed, until a new gynecologist arrived at the clinic to substitute her former doctor and attend her. In addition, she felt uncomfortable in not being able to help her family as before, complaining about a lack of strength to care for her home and for her day job. Loren appeared to carry a lot of blame in not being able to attend to the social demands that she believed were her duty, whether in the role of mother, grandmother, or professional.

Louise and Ludmilla anchored themselves to their role as mothers (and in Ludmilla’s case, grandmother), making this their main reason for surviving the disease. However, they were convinced that they would not manage to overcome their battles against physical discomfort and change if they did not have the daily support and presence of their children. It appears that these two women placed themselves as completely dependent on their children’s attention in order to deal with their fears of the disease. This points to a lack of autonomy, or even a victimization, which ended up bringing pressure to their families (children), who were given the responsibility of being the women’s sole source of well-being and safety. This idea can be confirmed with the excerpt from Ludmilla’s interview: *“I put all my hope in the life of my grandson, who was born during my treatment and showed me how good it is to live. Without my children and without my grandson, I think I would already have died from this disease and the sadness it brings.”* (Ludmilla) Likewise, Louise also conditioned her well-being to the presence and proximity of her children.

The Brazilian women who were identified as having a **protected identity goal** had diverse experiences, culminating in transcending or not the disease. Cristina had a family history of breast cancer and watched both her mother and maternal aunt overcome adversity, finding a cure for the disease through treatment. Therefore, this woman was focused on the future, and not immersed in the losses of the present moment, such as the fact that she had no hair and was soon to be without breasts, as she already foresaw for herself a cure in a not too distant future. Cláudia talked about learning, through the dietary restrictions imposed by chemotherapy, to reeducate her diet. She reported that, at the moment of the interview, she felt better than she had before the disease, affirming that she had gained self-awareness of her own body during the process of facing cancer. Brigite, who was Evangelical, entrusted God with all her hopes, as well as her capacity for overcoming the suffering that stemmed from cancer. In a distinct manner from the other interviewees, the woman appeared to feel satisfied with this atonement; in other words, she saw her suffering as a way that God could help her, in life, rid herself of the sins she would pay for in death: *"God is so merciful that He offers us the chance to save ourselves in life, when our soul goes through suffering without complaint. I don't complain of anything with this disease, because I know that I'll be saved when I die, for having overcome this without objecting."* (Brigite)

Bruna and Carla were not able to experience transcendence from suffering. The first desired the hair and beauty she had before. The other, apart from complaining about her appearance, maintained an investigative posture, ensured by her professional identity, and was always evaluating every physical sign as a possible worsening of her condition. These two women were immersed in pain, doubts, and distress, without being able to visualize a positive ending for their lives.

Carolina, the only interviewee who considered herself a man, was frustrated by the physical and psychic losses, and could not conceive a better end for her suffering. She expressed anger, irony, hurt, sadness, and other feelings, all through words, tone of voice, and tears. An explanation for this was found in the studies of Charmaz (1995), who cited a text of her own authorship, dating from 1994, in which she clarifies that men, more often than women, adopt an all or nothing approach for identity goals when they become ill. In this manner, Charmaz concludes that they (men) place a higher interest upon recovering the past and their own prior identities. And, if they cannot visualize a chance of recovering all of their past identities, they abandon the fight and succumb to the disease.

Among the German women who were identified as having a **protected identity goal**, there were also situations of transcendence of self-regarding the disease, and for some, self-acceptance in face of loss. Liane, for example, lowered her identity goals, which previously, according to her report, would have been above average; with the disease, they were restructured for her self-preservation. She transcended suffering and stopped focusing on the need to remain beautiful and thin, wanting only for her measurements to be within healthy criteria, as her words show: *"I must say honestly, that for a woman of 63 years, a size 40 with all of these hormones I'm taking is very good! I liked my size 38, but today I see that my health is better than my measurements. (...)"* (Liane). She also changed posture regarding her children and grandchildren, refusing to babysit, as she considered that her health had to come first and wanted to be able to sleep for a while in the afternoon, something that was not possible with children around. Marlene was another who set her children more limits, forbidding them from smoking inside her house, for instance. Additionally, she accepted a change in roles, allowing her sons and daughters-in-law to help with household chores. Melinda also lowered some of her goals, having, for instance, relinquished her work in the Church — she no longer wanted to show people she was good for being a Christian, through working for God. The participant shared that she had found her best form of therapy in nature, during her daily walks: *“I am not going to deny that I feel strange things, such as immeasurable pain and heat. However, I am bigger than that. I discovered that nature is my best therapy. I go out for a walk and improve all my discomfort. (...)”* (Melinda)

On the other hand, Lisa, who also had a **protected identity goal**, was not well at the moment of the interview. She said she believed that something she had done in the past was responsible for the emergence of cancer, so she felt guilty. She accepted that she had suffered a slowing down of her daily rhythm, and that she had more difficulty in executing household chores, or in carrying out her informal role as caregiver for her father and mother-in-law. All the same, she was fearful for the future, as she felt she had no choices; in other words, she did not believe she had the autonomy to change circumstances such as her job: *“(...) But I still don’t know how to do that, I’m still going to go back to work. I think I can say then, that I feel disappointed in myself.* (Crying and sobbing). *I have no choice, I go taking it day-by-day, even feeling full of fragility.”* (Lisa)

Matilda was an unprecedented exception in the study, as even with a **protected identity goal**, she appeared to completely neglect the gravity of her disease. She reported, and this was observed, that she was overcome due to her husband being bedridden. However, she did not imagine the possibility of caring for herself, of taking time for her body and her pain, when facing the disease. This woman spoke the least among all of the German interviewees; however, she made important contributions even with her silence. She did not know how to explain, for example, what she had gone through during chemotherapy, or how she had managed to care for herself and her husband while suffering from the side effects of the treatment. Returning to an excerpt that caused the researcher sadness during the interview: *“I don’t know what else life wants from me. See how he* (husband) *shouts! Today I’ve already given him his bath, his food, I’ve changed his diaper, and he’s had his medicine. But he still moans the whole time. Therefore, I have no peace.”* (Matilda). In this excerpt, it is possible to note how Matilda credits all of her suffering to the situation with her husband; it also highlights her lack of hope, in not knowing what else life will demand of her. It was clear she had immense difficulties with her husband. But what about herself? She could not say how she had gone through her adversities, what she was feeling during the day-to-day of treatments, or what she felt at that moment. She had no support network and did not identify in anyone a source of support she could turn to. The conclusion is that, if at some point she had suffered conflicts between self and sick body, she was not aware of it, and therefore this did not come up in her interview.

The situation that Matilda was experiencing was not a natural phenomenon in contemporary families, even though at times these might ignore and abandon their elders to their own luck, especially due to capitalism and its demands. It is, however, a problem that can be associated to an interventionist State and all the social insurances it brings, as explains Teixeira (2013). The State modified the lives of families and of other informal providers of well-being, such as neighborhood and community, since by trying to ensure the functioning of capitalism, it excluded people for being responsible for each other. When the State assumes too many functions, taking on even those that were previously exercised by these other groups, it leaves a vacuum that places mainly the elderly and children in situations of social vulnerability.

In sum, the positionings of some of the Brazilian and German women brought gains, with a consequent reduction of suffering, and a transcendence of the self beyond identification with the disease. Other positionings brought losses, some of which led the women to succumb to suffering, when the self could not adapt to the new reality of the body or the circumstances that they found themselves in. Among all the women, different identity goals were observed; however, this did not define if they would have more losses or gains, in direct relation to their choices within the hierarchy of identities. The main differences between them, and that guaranteed more better days than worse in the fight against the disease, were associated to their capacity for directing their attention to themselves, beyond physical aspects or social expectations, and reaching self-acceptance. When they placed themselves as priorities within their own existence — something that was not possible for all — they were more capable of transcending their self, and of freeing themselves from identities tied to the disease. This phenomenon was evident among all groups in the study, with more or less intensity, spanning from the richest to the poorest women.

4.5.3 Identifying a space for faith

For the Brazilian women, faith was observed among the postures adopted by some of the participants, such as Aurora and Beatriz, who had issues with their husbands during illness, and stated they had found a source of support for themselves in God. In the words of Aurora: *"I confirm to you, that if I were not a woman of faith, I would have fallen, I would not have been able to stand it, because what he* (husband) *does to me, I could already be in a depression. But thank God, nothing, what God gave me was courage!! (...)"* Besides being her source of strength, Beatriz delegated to God the role of helper in psychological aspects: *"(...) I was seen by a psychologist there* (at an NGO) *twice, but I decided to stop. Not because the psychologist wasn't professional, she was great! But because I think we have to get closer to God, first, (...) only He has the answers".* (Beatriz)

Brigite's situation was unique, as she was single and very lonely. She explained that her faith came from growing up in a religious Evangelical family.[12] This led her to believe, like her parents, that diseases like cancer manifest to make a person go through trials and remain faithful to God. She also believed that God had given power and knowledge to doctors to bring cures for human problems, as seen in the following excerpt: *"Doctors, like us, are instruments in the hands of God. God gives them knowledge, and they bring us the cure."* (Brigite)

Bianca, an interviewee who declared she had not followed any religion before she had cancer, became a practicing Catholic after her diagnosis. For this woman, faith was an important resource in the fight against the disease. In her words: *"(...) And another thing, I had no faith, none! I had faith in nothing, and I was cured by my faith! Because after the disease, I clung to God, I started being a practicing Catholic and today I know all the prayers. (...)"* (Bianca)

However, it is important to note that, beyond these 4 (four) participants, the rest of the Brazilian women did not mention faith or religiosity in relation to facing the disease. Among the poorest women in the study, the participants in group C, faith, religiosity, or even God, were not resources they turned to as support in dealing with the adversities of cancer. Even though some of them made sporadic mentions about faith, this was not identified as a "midway path" in the fight against the disease. Carolina, for instance, spoke of God several

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[12] To belong to an Evangelical religion in Brazil means being associated to a Christian Church, even if the form of worship is different. "Differently than what takes place in the United States, a country with a higher number of Protestants, in Brazil, the term evangelical is used to refer both to the historic Protestant denominations — Lutheran, Methodist, Baptist, Presbyterian,(...) — as to the Pentecostals — Christian Congregation in Brazil, Assembly of God, Church of the Foursquare Gospel, God is Love, Brazil for Christ (...)" (Gonçalves & Pedra, 2017, p. 71 - 72)

times, but did not demonstrate trust in divine resources for her cure; a posture found in the reports of the other women.

Among the Germans, contrary to most Brazilians, many spoke of God, faith, and religiosity as a path in overcoming the disease. Only participants Karen, Layla, Ludmilla, and Matilda did not mention God as one of their sources for support and strength in the fight against cancer. The remaining participants named faith as one of their key support pillars in dealing with sickness, as in the case of Larissa, Lisa, Marlene, Louise, and Mia. This excerpt from Lisa's interview helps clarify this positioning, which was similar in essence among the women: *"I must say that faith helps me a lot. When I feel pain, a deep doubt, I turn to God. In the silence of a prayer, I feel that He brings me strength, assists me, brings me tranquility."* (Lisa)

The reports of Melinda, Loren, and Liane placed greater emphasis on religiosity, mentioning God, Jesus Christ, and Saint Crescentia in terms of support and care, and speaking of situations they had experienced and which they associated with miracles. Additionally, Melinda spoke often of her work with the Church, her pilgrimages, and the acts of God in her life: *"God is the structure of my family. He cares for everything, allows the disease to allow the cure. We are faithful people in this home, and we see the small daily miracles that He performs."* (Melinda) Loren mentioned carrying a sort of amulet that her daughter had made her for protection during treatment, containing saint medallions, prayers, and other small trinkets. And Liane said that Jesus was always with her, caring for her even more at that moment when she needed help. She described an experience she had with Jesus while still a child, as a way of explaining the reasons for her faith: *"Do you have faith? (...) I have to say that I had a personal encounter with Christ, when I was around 5 or 6 years old. I wasn't delirious, I had a sort of lucid dream. (...) And from that day on, I started going to Church and never again lost faith. (...)."* (Liane)

The results of the study, in terms of the participants' faith, were unexpected, as they diverged from the observations of some authors, who point to a decline of Christianity in Europe and the simultaneous rise of it in Latin America. This led to an attempt to understand other nuances of the phenomenon, since many of the Germans declared they were practicing Catholics, and a number of ideas emerged that point to a possible association between well-being and religiosity in the European country.

Bingemer (2009) states that the changes that took place in the 19th century, and especially the second half of the 20th century, transformed the role of religion — and especially Christianity — in the lives of people all over the world. According to the author, the number of Christians declined in Europe, where it had initially grown and spread throughout the world; at the same time, the number grew in the Americas and even in some regions of Africa. For Guarino (2014, p. 3), *"in the first half of the 20th century, two large world wars exploded in the heart of rationalist, scientific, and technological Europe",* leaving the population — that had been sustained by the ideals of illuminism, which were widespread and entrenched in the continent — lost and forsaken without the faith in God of the previous centuries. At this moment, the European people lost their faith in humanity, which had brought Nazism, Fascism, and the extermination of many. According to the author, religiosity returned to the contemporary world in a heightened manner, with sects and fundamentalisms that spread and provoked conflicts all over the planet. The author describes critically what occurred in the Latin-American country: *"In Brazil, for example, we can observe in the National Congress, a powerful faction which connects several religious sectors in the sense of making decisions, creating laws, voting for measures according to religious morals."* (Guarino, 2014, p. 5).

However, it is important to point out that an interconnection between religion and the daily lives of citizens does not exist in Brazil alone. According to Hien (2014), despite the decline of Catholicism in Germany, there are still many Christians, as well as a large number of people who claim to be Catholic, even if they don't effectively take part in Church rites. For the author, there are issues between the German State and some churches that have hugely expanded their involvement in the provision of faith-based welfare, something that started in the early 1960s and had continued to grow. He states that the 2012 yearly report from Caritas — an institution of the Catholic Church which operates on a broad scale in the country — listed 559,526 employees, making it the largest private employer in the country. Hien (2014) points out that, different from other employers, Caritas and Diakonie (another Church-based institution) are not subject to the same federal laws in terms of worker's rights. This is because Article 140 of the German constitution allows the Catholic Church to condition job contracts to conformity regarding their cosmovision (firing divorcees, not accepting homosexuals for certain jobs, and other precepts that do not align with equal rights).

Hien (2014) cites other authors who point to Bismarck and Cavour (an Italian statesman) as pioneers in removing from religious organizations the prerogatives of providing welfare, with the intent of setting up liberal states that were independent from Churches. However, although at the start of nationalization welfare was predominantly offered by State institutions, the return of religious providers after World War II can be interpreted as a reversal of this process. If at first this leads us to think that, without the faithful, the Christian

Churches could not keep up their acts of welfare provision, soon we note that, besides maintaining their faithful, they have also grown as employers. This phenomenon was also registered by the author as a paradox regarding other authors from different industrialized and advanced countries in the 21st century. Naumann — 2005, cited by Hien (2014), highlighted the importance of the Catholic world vision in strengthening family politics after World War II in Germany; while Van Kersbergen — 1995, suggested that religion is a link, promoting an alliance between classes, encompassing many of the characteristics of the regimes of European Christian democracies.

In support with the research data, which was carried out in Bavaria, we find the work of Erasmus (2018) on the political strength of Catholicism in that German state. According to Erasmus (2018), Premier Markus Söder, going against the proposals of a secular State, decreed that a crucifix be displayed in all the regional offices of the Bavarian government. The Premier, who was backed by other politicians and by the people, also stated that the act revealed a *"commitment to the identity and culture of Bavaria".* (Erasmus, 2018, p. 1) This may help understand why the German participants from groups L and M talked so often of their faith and religiosity; possibly due to a process that involves tradition and identity in the German state they reside in.

Finally, it is worth noting some of the qualitative studies that directly associate experiences with religiosity during breast cancer. Couto and Dias Júnior (2016), based on the in-depth analysis of interviews with 19 women with breast cancer, made evident in their conclusion that the women related their cure to their faith and, in some cases, underwent a strengthening of their religiosity due to their experience with the disease. Veit and Castro (2013), by means of bibliographic research, identified that religious involvement, most of the time, is connected to the physical and mental health of people with cancer, contributing toward their quality of life in different aspects.

4.6 THESIS: “Appearance as a social value” versus “the social value of productivity”

This research adopts a similar perspective to that of Charmaz (1995), which in agreement with the positioning of other authors, considers that social existence essentially means a life in a material body; thus, a human being is made up of a “self” that is inseparable from the body it inhabits. However, self and body are not identical; they coexist in a continuous relationship, as they are inseparable. When people get sick, or go through permanent or reversible bodily losses, the relationship between the self and the body can be damaged, provoking a disturbance in the self-body unity. This damage may be higher for younger people, for whom changes are more sudden than for those who have experienced aging, which brings its own physical changes. Charmaz (1995) also considers that the meanings of the losses will be strongly connected to the suppositions and discourses about the body that the ill person already carries.

The Brazilian women interviewed were younger than the Germans, and that might be an additional factor to the side effects of chemotherapy, helping explain why these interviewees emphasized their physical losses more than the German women did. For the Brazilians, appearance was considered a social value. They suffered from the changes in body measurements — since most lost or gained weight with treatment — as well as from hair loss, bringing some a strong sense of embarrassment regarding social exposure.

The German women were, as a group, older than the Brazilians, and their losses were associated to limitations in executing daily activities. They complained of excess fatigue, and with it, their difficulties in carrying out productive tasks, such as cleaning their houses, wiping windowpanes, cutting the grass in the garden, or even doing volunteer work, such as ecclesiastic services (mentioned by one interviewee) or community events (mentioned by three of the women). In Layla's words: *"Honestly, I feel terrible because I am no longer a productive person like I was before. We live in an evolved society, and certainly have more quality of life than in other countries. But we work hard for that! (...) We give a lot of value to work."* (Layla) The Germans were observed to have identities that were more connected to their tasks, in general. Three of the women — Loren, Louise, and Ludmilla — who were not yet retired and had already returned to work, were afraid they would no longer have the same performance as before. And the 2 (two) who would soon return to work, Marlene and Lisa, were concerned about how they would deal with it.

Regarding identity, the research followed the symbolic interactionist perspective proposed by Charmaz (1995; 2009), which uses the concept of authors such as Mead (1984), discussing that personal identity is how the individual defines, locates, and differentiates self from others. Mead, one of the precursors of Social Psychology, suggests that this branch should consider self in the subjective matrix that defines it, as it (self) is formed by an intersubjective process, ensured by symbolic communication. Additionally, Mead (1992) explains the social behavior of individuals who, when assuming their social roles, in the different relationships they establish with each other, internalize the structures of the self, finding thus their identities. For the author, this happens as the subject begins to differentiate itself from the others with whom they interact, while at the same time assimilating and internalizing ideas extracted from the social medium itself. Thus, identity is based on a subjective matrix that guarantees the individual a process of self-understanding, in which they gradually recognize what they carry within that comes from others, as well as what they carry within that differentiates them from this other.

Finally, the study showed evidence that the Brazilian women had identities that were more focused on “appearance as social value”, while the Germans’ were more defined by “the social value of productivity.”

4.6.1 Comparing concepts of body and the generations found in the study

The age differences between the women, first within national groups, and then comparing the data found for both countries, made evident the need for a subchapter to discuss possible divergences between concepts of body among the distinct generations identified in the study. Breast cancer affects, among other aspects, a woman’s physical body, which led to the discussions carried out in Part II and III of the study. For the Brazilians (age between 35-65 years), no changes were observed, regarding the discourses that encompassed the body and its components, that pointed directly to concepts connected to their age groups. Among the Germans (age between 50-81 years), however, many spoke of the subject, mentioning that younger women care for their bodies in a different manner than older women do.

First, it is necessary to define the term generation, which can involve different concepts; for this, we return to the work of Motta and Weller (2010):

> Social scientists have sought to overcome this fact by acting in two fundamental directions in studies and research on generations. First, in the anthropological tradition, referring mainly to several forms of groups and age categories, in a sense of genealogy or of affiliation, while maintaining a classifying sense or function that includes both the positions in the family and the wider social organization. More recently, the works have embraced another dimension, more directly sociological and political, emphasizing the relationships between generations, in a recognition that this is about relationships of power — both in the family sphere and in the macrosocial scenario of solidarities and conflicts between generations, especially when directed toward matters of social policies, with emphasis on social protection and the arguable debate on equity between generations. (Motta & Weller, 2010, p. 176)

In this research, the term generation that was adopted straddles both meanings in the field of Sociology, as mentioned by authors Motta and Weller (2010): both that which points to anthropological tradition — classifying by age category, role, and family and social organization; and that which points to political dimensions — using relationships of power, inside and outside the family, as well as conflicts between generational groups, situating generations within discourses on equity. Motta and Weller (2010) also explain that what defines generations are the tendencies that form a sense of collectivity, with social actors identifying as belonging to certain groups or not; citing the ideas of Mannheim – 1964. From a perspective of Mannheim's work, analyzing the generational relationships of a determined group involves, besides age groups, a gaze on the positions of individuals in the collectives that make up the historic processes they are inserted in, as well as the tendencies they show for change or permanence, in terms of the concepts constructed within these collectives.

Comazzetto, Vasconcelos, Perrone, and Gonçalves (2016) list the names used for generations that interrelate in the realities of the job market; terminologies accepted by international sociologists that work with research in economy: a) Baby Boomer Generation; b) Generation X, and c) Generation Y. The Baby Boomer generation is comprised of those born in the last century, up to the year 1964. The individuals of this generation are connected and dedicated to work, placing value on their careers and on stability, being highly committed to their functions and also to social work. The Baby Boomers, especially in post-war Europe, grew up at a time of economic scarcity, having to work hard to reconstruct the job structure and reorganize the communities they were inserted in.

Generation X includes those born between 1965 and 1977, and who did not have much contact with technology when entering the work market. This generation experienced more job instability when beginning work, due to general changes in the corporate world. Also, it is made up of people with more feelings of helplessness, as their mothers mostly worked away from home. This would also be the reason that children had less of a reference for limits. (Comazzetto et al., 2016).

Generation Y, made up by those born from 1978 to the current century, mostly grew up in the age of technology, having known electronics since childhood, which grew more and more sophisticated. Those in Generation Y, *"in the world scenario, they witnessed the culture of impermanence and the lack of guarantees, due to volatile markets. (...) Living with family diversity, having spent their childhood with a schedule full of activities and of electronic devices, (...)"*. (Comazzetto, et al., 2016, p. 147). Within this perspective, these people are less rigid toward themselves, and more versatile and capable of adapting quickly to change. (Comazzetto et al., 2016).

Among the Brazilians, the four youngest women interviewed could be seen as belonging to Generation Y: Ana, Bianca, Cássia, and Cristina, born between 1979 and 1982. Generation X was also represented in the study, with five women: Aline, Beatriz, Bruna, Carolina, and Camila, born between 1967 and 1975. The oldest generation, made up of six of the Brazilians, represented the Baby Boomers: Aurora, Antônia, Brigite, Cláudia, Carla, and Clarisse, born between 1953 and 1964.

The German participants had no representatives from Generation Y, and only three of the women belonged to Generation X: Loren, Louise, and Ludmilla, born between 1965 and 1968. The other nine)participants were all women who represented the Baby Boomer generation, although the age difference was substantial: Karen, Larissa, Layla, Liane, Lia, Marlene, Matilda, Melinda, and Mia, born between 1937 and 1959.

The results of the study in Brazil showed a valuing of the body, socially constructed, and shared by the women. From the youngest to the oldest participants, the reports pointed at similarly described experiences that referred to this social construction of their bodies. The participants considered that Brazilian women were, in general, vain — caring for their hair, worrying about their weight, and watching the measurements of their waists and hips as well as the size of their breasts. However, some women posed critical questions about this, and did not legitimize the effectiveness of the discourse about body in their own cases. For example, while Antônia — from the Baby Boomer generation — said that she considered that most Brazilian women were concerned about being thin, something she knew from childhood, when her mother and aunts tried different formulas to lose weight, she herself did not care about this matter. Antônia stated that she would like a healthy body weight. On the other hand, another woman from her generation, Cláudia, sought to lose weight at any cost, having in the past undergone bariatric surgery to reduce her stomach and consequently lose weight. Most of the women from the Baby Boomer generation felt the same way as Cláudia.

For Generation X, among the Brazilians there were also reports that showed a submission to the social imperatives that considered being thin as something of value. Beatriz, for example, said: *“(...) I didn’t have a waistline the way I wanted, it wasn’t trim enough, and my breasts, after I breastfed, were no longer pretty, my stomach was already large; that would sometimes send me to bed, depressed!(...)”* (Beatriz) This report referred to the past, before the experience of breast cancer, when she sought to have a thinner body, with firm breasts and a trim waist. Like her, other women followed the notion of a standard for their bodies, even if they couldn’t reach their idealized measurements. Out of the Generation X women, only Camila did not strive to be thin, and reported never having done so. She recognized the standard that mandated that a thin body was a beautiful body but did not give this any importance: *“There are many women who want to be thin to be beautiful. I think I’m* *pretty, plump, I've always been this way. I know I should lose weight for my health, because the doctor told me that in my case it's obesity. (...)"* (Camila)

Different from the rest, the women in Generation Y, only found among the Brazilians, were unanimous in saying that they recognized the socially imposed body standards that valued being thin. Among these women, none reported that they were or had been a person who worried about body weight, demonstrating less vulnerability to the social discourses about the body. In Cristina's words: *"I always tell the girls, my friends, some seek perfection, others not so much! I'm at peace, the way I am, it's fine for me! (...)"* (Cristina) Another social actor with important contributions was Ana, who said:

> I think that sometimes, women worry too much about their exterior appearance and not in caring for the interior. Sometimes, women worry too much in getting silicone and Botox, but not in going to the gym every day for their own health. (...) It's rare to find women who don't only care about their exterior, but also their interior, and what I call interior, is not this story of I'm thin or fat, but something like "have I already been to the mastologist this year?" (...) So I see women worrying a lot about their looks, especially now with this virtual issue *(referring to the internet and social networks).* So many photos to post… Women want to show off virtually, but sometimes they don't look inside themselves. Then we see such devastating illnesses, because the culture has been a culture of the virtual, of appearance, and people have looked very little at themselves, at what they feel and think. I'm different, I focus my attention on myself, and I don't do things without reflecting why. (Ana)

Ana, like the other women in Generation Y, was more critical toward the socially propagated discourses regarding being thin, disparaging physical exercise for reasons associated simply to bodily beauty, as well as the need of Brazilian women to always post photos on the internet, where they opt for angles that show off their bodies, hair, or other aspects socially seen as beautiful.

At this point, in order to discuss the positioning of the German women, it is important to mention that none of them answered, without reservations, the question about what they thought of the relationship of women in their country with their own bodies. They always warned that the answers would be limited to observations about their social circle, including daughters, friends, or acquaintances. These women made it clear that they would not, or could not, speak about Germans in general, but only about the German women they knew. And the data analyzed stems from their reports, even though these were directed, and were specific and not generalized.

Among the Germans in Generation X, some of the women worried about their measurements. Ludmilla complained several times that she had gained weight, which she considered the worst of the challenges she had faced with breast cancer. She thought that a thinner woman was a more beautiful woman: *"In my opinion, a woman is more beautiful when she is thinner. Fat people do not look well in their clothes. (...) So I think that my acquaintances also think as I do".* (Ludmilla) Louise frequented a gym, taking part in physical activities in order to maintain her body thin and in condition, as she explained: *"I am very satisfied because I have been released to go to the fitness studio again. I think that body training helps to maintain a thinner and more shapely body."* (Louise) She also criticized her daughter, saying she was slovenly, was chubby, and did nothing to change this: *"(...) My son plays soccer, is thin and conditioned like I am. Now, my daughter has been chubby for a few years, and she doesn't even care about it. It's like she doesn't care that her stomach sticks out more each day. She must take after her dad!* (laughter)*"* (Louise). Loren, who did not seem to care if her body was in shape or not, complained that chemotherapy had changed her taste buds, and made her gain weight, because it led her to consume more sweet food. However, she did not signal this weight gain as a problem to be solved.

Among the Germans in the study, the Baby Boomer generation — which, according to authors Comazzetto, Vasconcelos, Perrone, and Gonçalves (2016) is the one that most values formal work and productivity — was divided in two groups: women born up to 1950 (Karen, Matilda, Melinda, and Mia), and those born after 1951 (Larissa, Layla, Liane, Lisa, and Marlene). This division took into consideration the age differences within that generation, as well as different ways of thinking. Among the older Germans, it was possible to identify that only Karen showed a preoccupation with her body, reporting on how she used to take care, practice sports, keep her body in shape, and other statements of the sort. Her sporting conduct was kept up from her youth until she turned 70, when she was diagnosed with a heart arrythmia and found herself obliged to reduce her pace in terms of sports practice. She also spoke of vanity, considering herself and her friends as vain women. However, cancer had further reduced her rhythm, leading, for instance, to the hiring of a cleaner to help care for her house, since she could no longer do that alone. The other older women did not talk about their own concerns regarding their bodies, or of beauty aspects. Melinda, however, observed that her daughters had distinct forms of physical self-care, one being a sports enthusiast, while the other was always in appointments with doctors or other medical professionals, remaining vigilant in these matters. Matilda said that, in the past, before her husband was dependent on her care, she liked to go for bike rides and contemplate nature: *"I had a habit that was very good for my body, it would alleviate my back pain and make me feel good: I would ride my bike, contemplating nature. But it's been a long time, (...). I have to stay here always, near him.* (husband)" (Matilda)

Among the younger German Baby Boomers, only Liane spoke of vanity and of caring for her weight, her hair, and overall, her appearance. She said: *"I no longer dye my hair as I did before, every 15 days, that would be too much pressure. But I use a spray that camouflages the gray hairs, so I can keep looking young and attractive. (...)"* (Liane) Marlene, who had been through chemotherapy, did not mention any issues linked to her appearance, and did not complain about losing her hair or changing her weight, although she did talk about her concern for her body because of the involuntary exposure to noxious agents such as cigarettes, which she considered a terrible social habit, popular among her relatives and acquaintances. None of the other women in this age group complained about their relationship with their bodies or mentioned this as problematic. Lisa, however, perceived this as a generational issue, stating: *"(...) You care for yourselves, for your bodies. You do physical activities and think of yourselves, of your figure. It wasn't shown to us, in our generation, that the self is also important, that the body should be considered important so the person can have health. (...)"* (Lisa) For her, younger women gave more value to caring for their own bodies; all the same, Lisa did not associate her thoughts to beauty aspects, but to health.

For both publics in the study, it was observed that the body was more valued by the women in Generation X in both countries. However, among the Brazilians, those in Generation Y criticized submission to discourse about the body. As for the Baby Boomers from both countries, there were women who cared for their body out of vanity or for health; however, the Germans appeared less concerned about being thin or body measurements.

As for the aspects related to the appreciation and involvement with the formal work, of all generations identified in the study, in both countries, most women reported that they had assumed duties paid employment throughout their lives. The difference between Brazilians and Germans women on this topic is that the first group did not emphasize their concerns with chores, neither inside nor outside the home. They worked outside the home, but it was considered a source of livelihood and it was not associated with moral duties and social recognition. As for the Germans, who mostly came from the Baby Boomers Generation, paid work was highly valued, being a source of pride for these women; in this sense, the study corroborates the statements of Comazzetto, Vasconcelos, Perrone and Gonçalves (2016), that such generation has a greater commitment to formal work.

4.6.2 Critical considerations on society, politics, and illness management

The Brazilian study pointed to a concept of body as a social value, including being thin and in shape, having well-cared-for hair, and other aspects of external experience in general — ideas which were shared between most of the interviewees, with few exceptions. In Germany, the women predominantly appreciated moral values, such as the ability to work inside and outside the home, as being important to themselves and their acquaintances, as discussed in item 3.6.1.

The Brazilian interviewees showed a higher preoccupation with vanity, corroborating the research of anthropologist Miriam Goldenberg, who wrote about women and their relationship with their bodies and with aging, in an article comparing these processes between Brazilian and German women – The body as capital: Gender, marriage, and aging in Brazilian culture - Goldenberg (2010).

For Goldenberg (2010), who worked with women between 50 and 60 years of age — therefore in the Baby Boomer generation — from the middle and upper classes in Rio de Janeiro and Germany, the results of her study indicated both losses and gains of the aging process, as she concluded. The women studied by Goldenberg in Brazil were married or divorced, all had children, and some still worked while others were retired. In general, the author states that the majority of the Brazilians were dependent on their husbands, not as provider, but as the one who gave them social visibility. These women were very concerned about their bodies' aging process, fearing rejection by their husbands. As for the Germans in the study, all were in the same age group as the Brazilians, however, they all worked, and were active and independent, both economically and subjectively. Some had children while others did not, as a legitimate choice, and the same applied to being married or not. The last were women, in Goldenberg's perspective, from the post-war and post-feminist-movement generation, and they weren't as concerned with their aging and with what their partners might think of that. It is worth noting, in this author's studies, the discrepancy for the Brazilians regarding financial independence and affective dependence:

> Already in the first interviews I noted an abyss between the objective power that the Brazilians had conquered in different domains (professional achievement, financial independence, higher education level, freedom in affective and sexual life) and the subjective misery that emerged in their discourse (preoccupation with disease, excess weight, body shame, fear of solitude and sense of invisibility). (...) The discrepancy between the objective reality and the discursive misery of the Brazilians demonstrates that aging here is a much bigger issue, which can explain the sacrifice made by many to appear young. (Goldenberg, 2010, p.195).

However, some of the statements made by Goldenberg (2010) are called into question when compared to the results of the present study. The research data, as discussed, reveals a social construction of the body's value, established in the analysis of the reports of the Brazilian women interviewed. This goes beyond their interest in keeping or seeking a partner, and points instead to their need for social insertion, or to be accepted by other women. Thus, we should not readily take the anthropologist's affirmation about *"subjective misery"* in a generalized sense, as something that stands out in the discourse of the Brazilians, as it is believed that power, knowledge, and sexuality, as well the interconnections between these and discourse on the body, should not be analyzed outside of a wider historical context, as suggested by Foucault (1988), Scott (1990), and Butler (2015b).

The Brazilians in this study proved to be generous, caring with each other, and open to give or receive care from other women, who like them, had breast cancer. They showed mastery in building formal or informal support networks, discussed in "Strengthening yourself, strengthening others", item 2.5.3 of the text. More than half the interviewees had experience with these support networks — 9 (nine) women, distributed among all the research groups (A, B, and C). The phenomenon emerged for the Brazilians as an important support strategy in the fight against the disease. The participants made it clear that, by means of these support networks, which were not made up of family or health professionals, they acquired more knowledge on managing the disease. In addition, they found freedom to discuss subjects that were hard to approach with family members, such as fear of death or sexuality issues.

Among the Germans, more individual and even individualistic strategies for facing the disease were observed, as several said they did not allow themselves to exchange experiences with other women, regarding the fight against the disease. This was discussed previously through the reports of Mia and Liane, who did not wish to speak of the subject with their acquaintances for fear of being judged, or so as not to suffer in advance about treatments. The subject also appears in this extract from Loren's interview: *"This disease has shown me that I have no friends, besides my daughters. In the fight to survive these treatments, I discovered it's each one for themselves, and God for all. I didn't see a single other person extend their hands to me*. (...)" (Loren)

Regarding the excessive preoccupation of the Brazilians with their bodies, and with vanity, as well as with health or sickness, this matter was understood in this study as relating to interpenetrating issues of power — often dictated by medical knowledge, according to Foucault (2005a; 2005b); or of knowledge — disseminated not just by scientific means, but by the "networks of micropowers" that generate social persuasion, again according to

Foucault (2003). The Brazilian woman is also subjugated by issues of the body; a body that must have certain measurements and components, such as breasts and hair, to affirm femininity and belonging to groups of women, as the study makes clear.

Thus, Brazilian women are not born vain — they learn to care for and to value exterior appearance, as well as certain specific characteristics of their bodies, such as breasts, waist, or hair, as part of their social interaction, as discussed in item 2.6.1. However, the experience of living through sudden change with breast cancer demanded from these women an adaptation of the self to their new physical realities, at the cost of succumbing to an identification with the disease and the damages it imposes on the body. Among them, the greatest challenge was overcoming hair loss, as all the women interviewed had suffered from alopecia. For the Brazilians, hair was immediately noticed by people, both known and strangers, who would see them with scarves or wigs and show consternation, discomfort, or pity.

Alopecia is a stigma of breast cancer, according to authors such as Reis and Grandim (2018), Assis and Fernandes (2017), and Araújo and Fernandes (2008). However, many interviewees appeared to have overcome the loss of hair — at the time of the interviews, some still had no hair, while others were growing it back. This process of overcoming, which involved self-acceptance, pointed to a higher success in the fight against cancer. However, 4 (four) participants were not able to accept hair loss: Carolina — who identified as a man, Clarisse, Bruna, and Carla, who showed less success in managing their losses and less self-acceptance.

Cássia's case was different, since she went through pregnancy soon after her cancer diagnosis and first chemotherapy treatments, and at the time of the interview had a one-month-old baby. The participant was very insecure, not due to any aspect of her appearance, but from the fear of not being able to survive if the disease were to advance, since her chemotherapy was delayed due to her pregnancy.

For the Germans, the experience with illness and treatment was not quite a counterpoint to aspects that directly impacted their appearance, despite not suffering as many body losses; even those who went through chemotherapy did not mention the impact of their physical losses on social inclusion. However, all interviewees declared they had developed a substantial exhaustion, which they associated to side effects of treatment. This damaged their capacity for productivity, as the different reports made clear. Thus, to go through adaptation, they also had to adjust their self to their new physical experiences.

The biggest challenge in illness, for the German women, was dealing with extreme fatigue, as they had a series of daily tasks they had to carry out. However, most of them managed to develop individual strategies to overcome this, such as napping on the sofa after lunch, as mentioned by some, or sleeping earlier than before, as others said they were doing. A few were not successful, and appeared confused, without perspective, or immersed in the losses stemming from the disease, as took place with Layla and Lisa, who did not know how to reduce the demands of productivity that they had previously taken on.

The behavior of the German women, who for the most part sought to naturalize, without questioning, the fact that they had a great excess of tasks, did not diverge from data found in the literature of the country on this phenomenon. A qualitative study made by researchers Jurczyk, Jentsch, Sailer, and Schier (2019) attempted to understand the fact that women were the mainstay of their families, and the implications of this in modifying the concept of gender, or the roles carried out within the family with basis on genre. The authors interviewed different couples in Western Germany where women were the head of the family. They observed that this responsibility for the financial support of the home did not release women from an overburdening of household chores, and from caregiving, especially childcare. According to the researchers, this disproportional amount of housework was seen by the women, heads of their families, as compensation for the right to work outside the home. In this manner, the authors observed an inclination by these women toward roles stipulated by the patriarchy. In addition, the authors highlighted that, in the German context, despite advances in legislation that seek gender equality, women are still the key caregivers and are the main ones responsible for household chores. Jurczyk, Jentsch, Sailer, and Schier (2019) also cite other authors whose research aligns with their work — Chesley, 2017; Bittman et al., 2003; Greenstein, 2000; Tichenor, 2005.

The document titled *Twenty-fifth Anniversary of the Fourth World Conference on Women and Adoption of the Beijing Declaration and Platform for Action (1995): Report of the Federal Republic of Germany,* produced by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (2019), brings a series of conquests and advances already in effect in the country, giving special emphasis to the measures adopted by the legislation to promote gender equality. According to the document, *"Article 3 of the German Basic Law stipulates the following: 'Men and Women have basic rights. The State must promote the effective implementation of equal rights for women and men and take measures to eliminate the disadvantages that exist now.'"* (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth; 2019, p. 1) But, despite different laws and decrees having been in vigor for some decades in the country, created based on the expectation of the implementation of Article 3, the document makes it clear that German women and those who live in Germany with permission, as immigrants or as refugees, still face many difficulties regarding social expectations, stereotypes, and a number of barriers which men do not face, or do so with a lower degree of difficulty. Meanwhile, Germany seeks to establish a society in which matters of gender are truly equal, here women, men, and the LGBTI+ population have the same opportunities, and not just the same rights. The expectation of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (2019) is that, gradually, based on the efforts of the different states that make up the country, the situation will change until data is more satisfactory at a federal level than at present.

However, Brazil's reality is very different. The country and its governors do not appear interested in overcoming gender issues, and the patriarchy remains evident in a number of sectors of social organization. This was clear in the study, which even had one participant with a post-graduate degree in Social Service, who despite this had been, for many years, a sexual object at the hands of her husband, and was even beaten at times. Saffioti (2004) explains that the social and sexual contract promotes the freedom and domination of men over women. The original contract creates the law of male sexual right, the means by which the modern patriarchy was constituted, the form of expression of the political powers. The author also sets out the idea of gender as a concept of multiple interpretations and different readings in feminism, with different emphases, although, from a consensual aspect, gender is the social construction of masculine and feminine. However, that alone would not explain the inequality between men and women present in Brazilian society.

Brazilian legislation already includes gender equality, as stated in this excerpt by Lima and Mourão: *"The principal of equality in Article 5 of the Federal Constitution of 1988 determines that all people be treated with isonomy, therefore independently of race, economic situation, sexual orientation, social class and sex, people should have equal treatment by the law."* (Lima & Mourão, 2019, p.1) In practice, however, the authors make clear that the majority of women are compared, in general within Brazilian society, to mere objects — this explains the excessive value placed on the body. Many have their choices restricted, even with regard to rights over their own bodies, as this would also be an object for satisfying men, serving for reproduction and for demonstrating male power. Lima and Mourão make note that the rights guaranteed by the Constitution are not capable of eradicating the inequalities between men and women in Brazil, since this depends on radical changes in the organization of society. Regardless, the authors see this as a possible path, and a tendency for new generations, seeing as in prior years a woman even occupied the Republic's Presidency.

Counter to this, we are observing a setback in the present Brazilian scenario, as the current Minister of the Family, of Woman and of Human Rights, Damares Alves, appointed by the President of the Republic at the time, Jair Messias Bolsonaro, does not concern herself with the findings of the different sciences about the need to face gender issues. As stated by Fuks (2019):

> The conjectures of minister Damares Alves on violence against women border on pathetic. In her eagerness to attribute to gender theory the burden of cruelty directed to the female sex, Damares reveals her contempt for any and all theory that could guide her in the ministerial function of promoting, among other things, public policies for the protection and emancipation of women. (Fuks, 2019, p. 1)

It seems to be part of the minister's performance to appear a simpleton when facing such a complex issue, and with this, she surreptitiously curbs the expansion of thought and the creation of efficient strategies for the combat of violence against women. Misogyny and feminicide date from the foundation of the first human societies and should not be analyzed by means of the ideological discourse that the minister embraces. However, overcoming the abyss that exists in equality between men and women in Brazil appears to still depend on a sum of other factors, beyond the macropolitical spheres. It is necessary for society to adopt a new posture regarding the objectification of women, and that women themselves become more aware of this.

Returning to the results of the study in Germany, Louise, Loren, and Ludmilla appeared less successful in facing the disease than the other participants since, in addition to the excess of tasks they shouldered, they placed themselves as subjectively dependent on their children, revealing little autonomy with regard to their own condition of well-being. In Lisa's case, she said she was a person without choices, subordinated to the demands of caring for her household, her father's household, and being partially responsible for her mother-in-law, while dealing with the distress of having to return to formal work, as her retirement had not been approved. These 4 (four) women also stood out for having cried during most of their interviews, making it clear that they were still fragilized by the subject of cancer and their experiences with the disease, as well as the losses it had brought. This data goes against the studies of Goldenberg (2010), who in comparing Brazilian and German women in terms of their losses from aging, states:

> (...) The Germans, in turn, revealed themselves not only more secure objectively, but also subjectively. They appeared more comfortable with aging and emphasized the richness of the

> moment they were living, in terms of quality of life and of professional, intellectual, and affective accomplishments. (Goldenberg, 2010, p. 195)

The losses with the disease cannot be directly compared to aging; however, some of the German interviewees did not demonstrate, in this study, that they were subjectively secure people. They felt uncomfortable for no longer being the same women as before, and ended up clinging to children/grandchildren, as well as their identities as mothers, as a strategy to protect themselves subjectively.

A special situation was that of Matilda, who had no support network besides the one made up of health care professionals. She was overburdened with household chores and with caring for her invalid husband, and revealed a sort of denial or belittling of her own illness.

For Foucault (2004a), freedom is the ontological condition of ethics. The caring for self, the moral administration, the ethos, appeared in the Greco-Roman world as an ethical exercise and simultaneously as a libertarian exercise, in which man was preoccupied by not becoming a slave to his passions, or of those who governed him, or those around him. This demanded self-knowledge. As the subject inserts themselves into a certain number of rules of conduct (truth and prescriptions of the social context), getting to know oneself implies connecting to the game of truth, in other words, identifying the "truths" which, in a way, constitute them. However, socioeconomic conditions favor the entry of the subject into this "game of truths", since money facilitates access to knowledge, which in turn facilitates access to different social contexts, to power, and, in last analysis, to self-knowledge.

Corroborating with the abovementioned work of Foucault, the results of this study revealed that most women in groups A and B in Brazil were more successful in facing the disease than the women in group C. In Germany, on the other hand, the women with the most success in terms of self-care could be found in all three groups of the study; however, in groups L and M, there were exceptions in terms of conclusion, and some women were immersed in loss and suffering, without much success in overcoming breast cancer and in self-acceptance.

Finally, we return to the work of Yingling (2018), who carried out a qualitative study by means of GT, that sought to compare the experiences of 12 women who had already overcome breast cancer treatment. The author, who worked with American subjects, concluded that women who are breast cancer survivors enact a sort of emotional negotiation in order to be able to win against the disease, which nonetheless leaves an impact upon their psyche. She calls attention to this, underlining that health care professionals should not neglect this phenomenon. Yingling, who adopted Glaserian GT, identified 5 types of emotional negotiation carried out by the women after beating the disease: loss of order of life; order of assisted life; transformation; acceptance; and creation of emotional order. This corroborates with the present research, as it was observed that the study participants, both German and Brazilian, had to adjust their emotional aspects, forming new negotiations with themselves in order to deal with the disease; and, the better they adjust their self-acceptance, the better they deal with life during breast cancer treatment.

CONCLUSION

5 CONCLUSION

At the end of the work, and with each part presenting conclusive analyses, presented in the Theses of the study, it is clear that the experience of breast cancer brought different challenges for both the Brazilian and German women. The issues of note include from discovery of the diagnosis to the daily management of the losses related to illness. However, in some respects, the experiences of these women could only be compared within their country groups, since there were large differences between the two participant publics.

Regarding discovery of the diagnosis, it was observed that the poorer Brazilians had more difficulty obtaining a confirmation of cancer than those more economically favored, while the poorer Germans did not have this problem. In addition, when comparing the experiences of the women from both studied publics, it was clear that the discovery of the disease happened in distinct ways. Most of the Brazilians noticed the presence of a nodule or other breast alterations themselves, and then sought to obtain a diagnosis. The situation for the Germans was different, as the majority discovered the disease by answering the exam invitation sent by their health insurance and submitting to a routine screening mammogram. Thus, this technique has been an important part of the German public health policy, pointing to a reduction of socioeconomic inequalities, and providing all women with a better access to a breast cancer diagnosis.

Other forms of discovery of the disease in Brazil were: routine gynecologist appointment, with the professional identifying the nodule and requesting exams — something that took place for some of the women; or outside insistence, as some of the poorer women in the study only sought a doctor’s appointment after a third party told them their pain could indicate breast cancer. In Germany, what stood out was self-discovery of the disease by some of the older participants in the study, who no longer qualified for the country’s screening programs, which focus exclusively on women between 50 and 69 years of age.

Regarding disclosure of the diagnosis, it was evident in the study that the women in both countries first told their affective partners about the discovery of cancer. Additionally, they also looked first to their partners for support, followed by their children, who also formed part of their support network. Another aspect that the study brought up was the wider support network, which for the Brazilians included sisters, relatives, friends, and even neighbors. For the Germans, the support network did not grow at any moment during illness, and was based only on the women’s immediate families, made up of children, sons or daughters-in-law, and their spouses. These women, for the most part, opted to preserve their privacy and not allow others to know they were dealing with breast cancer. This indicates that, for them, the stigma of the disease was more of an issue than for the Brazilians.

Another discovery of this study identified among the Brazilians was the relevance of formal or informal support networks, made up of other women who had, or had been through, breast cancer. After experiencing illness, the women in Brazil sought other women who were also dealing with the disease to assist them in different aspects such as the fear of death, issues related to sexuality, physical losses, and others. They described these experiences as successful and a source of strength in the fight against the disease.

With regard to treatments, these were very different when comparing Brazil and Germany, since medical prescriptions to treat breast cancer took distinct paths. All the Brazilians, without exception, underwent chemotherapy treatment, with only two participants going through radiotherapy. Only a third of the Germans, however, received a medical prescription for chemotherapy, while all of them, without exception, received radiotherapy. As the methodological sampling excluded women with cancer that had been identified at an advanced stage, the reasons that led to all the Brazilians receiving chemotherapy had no connection to a late stage of the disease. The data to which the researcher had access was not sufficient to clarify the chasm between medical approaches for cancer treatment in each country, since the diagnoses had similarities. Thus, the researcher has opted to register these differences without evaluating the subject in depth.

However, the treatments were a reason for some of the differences in managing illness, as they brought larger or smaller physical and psychological losses for the women who were submitted to the different procedures. Chemotherapy, for example, was greatly feared by the Germans, who spoke of the matter as a factor to escape from, and even reported that this had led to receiving compliments from their doctors. One German refused to submit to this type of treatment, making a choice that went contrary to medical opinion. The Brazilians compared chemotherapy to being hit by a tsunami, due to the quantity of side effects that the treatment brought. As these women could not escape it, they adapted to the circumstances and found ways of managing their new physical and/or psychic experiences.

Surgery, radiotherapy, and hormone therapy were also treatments experienced as invasive factors for different participants in the study. This helped to mark the experiences of suffering, which all the women underwent after being immersed in the fight against breast cancer. Thus, by following the perspectives of symbolic interactionism, different subjective positions emerged, as well as distinct identities or identity goals which the women adopted while dealing with the adversities that stemmed from illness.

Despite the research counting on a single interview, the fact that this was carried out in depth contributed in determining the women’s identity goals — at least at the time of the research. The women with better socioeconomic conditions, in both countries, predominantly adopted above average social identities, standing out for being capable of helping themselves and also others, despite their illness. Some of the Brazilians and one of the Germans who were recognized as having this type of identity goal took on a position of mastery toward the disease, attempting to share their ideas and manners of acting with other social actors.

The Brazilian women who appeared to have adopted a contingent identity, on the other hand, were divided, with some dealing better with the adversities of the disease, and others worse, naming God and/or their children as their motives for fighting the disease. Of the German women identified with this type of identity, all appeared to be immersed in suffering — which doesn’t mean they were going to succumb to cancer. However, they positioned themselves as victims in face of the disease, and were more passive than the others, demanding more attention, especially from their children. In the same manner, the women who adopted a protected identity goal also had a better or worse performance in terms of managing the losses that came with illness. And there were some distinct situations among these, such as one social actor in Brazil who identified as male, and was therefore distressed by the losses; also, a woman in Germany who, overcome by care demands for her invalid husband, appeared to neglect her own suffering with the disease.

Finally, some of the positionings adopted by women in both countries can be considered to have brought gains, and a certain reduction of suffering, by assisting them in transcending their own self, with assimilation superimposing the disease. Other positionings, on the other hand, brought damage and even coherent adherence to suffering, especially when the self did not adapt to the new reality of physical and/or psychological losses. And although different identity goals were observed within the two publics, this did not define if the women would have more losses or gains, which was directly related to their positions within the hierarchy of identities. In sum, they appeared to be better adapted when they were able to focus their attention upon themselves, with self-acceptance, freeing themselves from social conventions about the body, in the case of the Brazilians, or from social demands for productivity, both in a domestic context and in the broader social context, in the case of the German women.

The reports on becoming ill ended up revealing some aspects of the culture of both countries, placing the women in positions of disadvantage when compared to men. In Brazil, where there is a lot of value placed on physical form, both by men and by the women themselves, the abrupt bodily changes caused most of the indignation and suffering in the fight against the disease. The Germans, who live in a society where the female body does not appear to have been considered an object — at least not according to this study —, suffered when they felt confronted by their values, which included work, privacy, and responsibility. Within each society, the women had to overcome the shared values in order to better deal with illness.

Other important aspects were identified in this research, such as, for instance, the rehabilitation program offered in Germany as one of the guidelines in public policies for breast cancer. This program encompasses both the immediate demands of women, from physiotherapy to psychotherapy, as well as issues that emerge later on, such as reinsertion in the job market or education for the requisition of rights, through training.

Subjects such as faith or religiosity were discussion themes for both publics in the study, as were sports and health. The German women stood out in these topics in comparison to the Brazilians, since they asserted themselves as more religious, for the most part, as well as more assiduous practitioners of physical activity. These women also demonstrated a better knowledge than the Brazilians in terms of the rigorous selection of products to be consumed, such as food, medication, and others, and they spoke of their option for a natural diet as well as homeopathy and naturopathy, independent of the disease. This points to a wider dissemination of health concepts in this population.

5.1 Future perspectives

The researcher envisions repeating the study with the same women, within a two-year period, to verify their updated health conditions, as well as any changes in their identity goals. In addition, the intention is to prepare some form of material to allow the researcher to supply feedback of the current study to the women participating in it — in a less technical manner than the academic text itself.

The researcher also suggests that this work could be broadened by other scientists, in other areas of knowledge, for a better verification of treatment decisions and options — which held large discrepancies when comparing both countries. This theme deserves a careful investigation, since chemotherapy — prescribed to all the Brazilians in the study — brought significant issues for the women's physical and psychological health. The same took place among the German women who also underwent this treatment; however, they were a minority among the interviewees from this country. This indicates that, in Brazil, treatment brings more losses to the quality of life of women with breast cancer.

5.2 Limitations of the study

One of the issues with this research was the age difference between the Brazilian and German women, as the first were younger than the second. This factor may be one of the motives that affects concepts of body, as well as concepts of work and other social values that relate to generations. This was touched on very briefly within the study and would require more time for a detailed analysis that could better connect symbolic interactionism to the generations identified in the study.

Additionally, the research was carried out over a long period of time, with a two-year interval between the interviews carried out in Brazil and those that took place in Germany; this may already account for differences in how treatments are applied in the first country that was studied. Finally, having an opportunity to interview the doctors in both countries could have added to and broadened the study’s comprehension.

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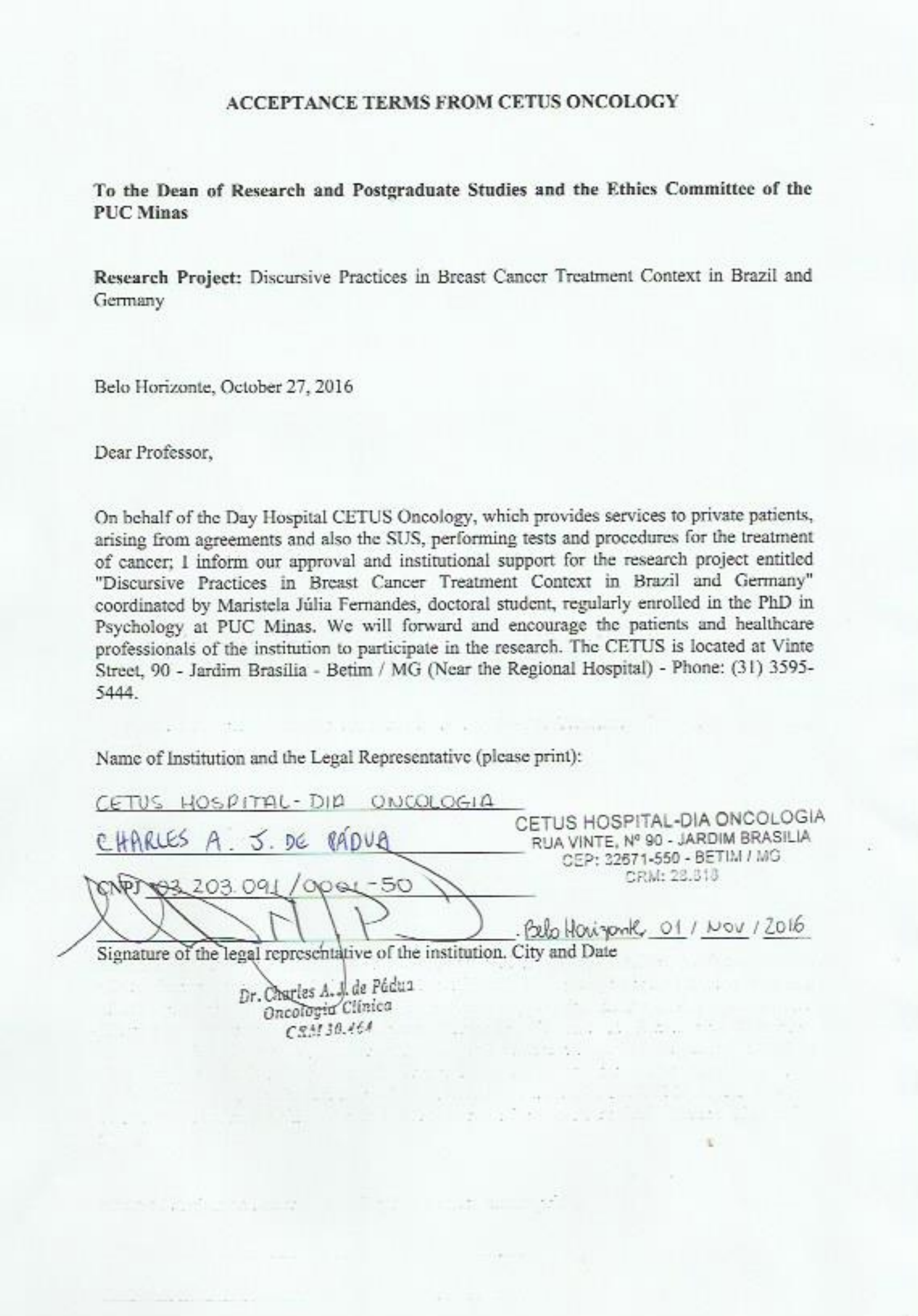
APPENDIX A: Agreement Form for CETUS Oncology



ACCEPTANCE TERMS FROM CETUS ONCOLOGY

To the Dean of Research and Postgraduate Studies and the Ethics Committee of the PUC Minas

Research Project: Discursive Practices in Breast Cancer Treatment Context in Brazil and Germany

Belo Horizonte, October 27, 2016

Dear Professor,

On behalf of the Day Hospital CETUS Oncology, which provides services to private patients, arising from agreements and also the SUS, performing tests and procedures for the treatment of cancer; I inform our approval and institutional support for the research project entitled "Discursive Practices in Breast Cancer Treatment Context in Brazil and Germany" coordinated by Maristela Júlia Fernandes, doctoral student, regularly enrolled in the PhD in Psychology at PUC Minas. We will forward and encourage the patients and healthcare professionals of the institution to participate in the research. The CETUS is located at Vinte Street, 90 - Jardim Brasilia - Betim / MG (Near the Regional Hospital) - Phone: (31) 3595-5444.

Name of Institution and the Legal Representative (please print):

CETUS HOSPITAL- DIA ONCOLOGIA

CHARLES A. J. DE PÁDUA

CNPJ 03.203.091/0001-50

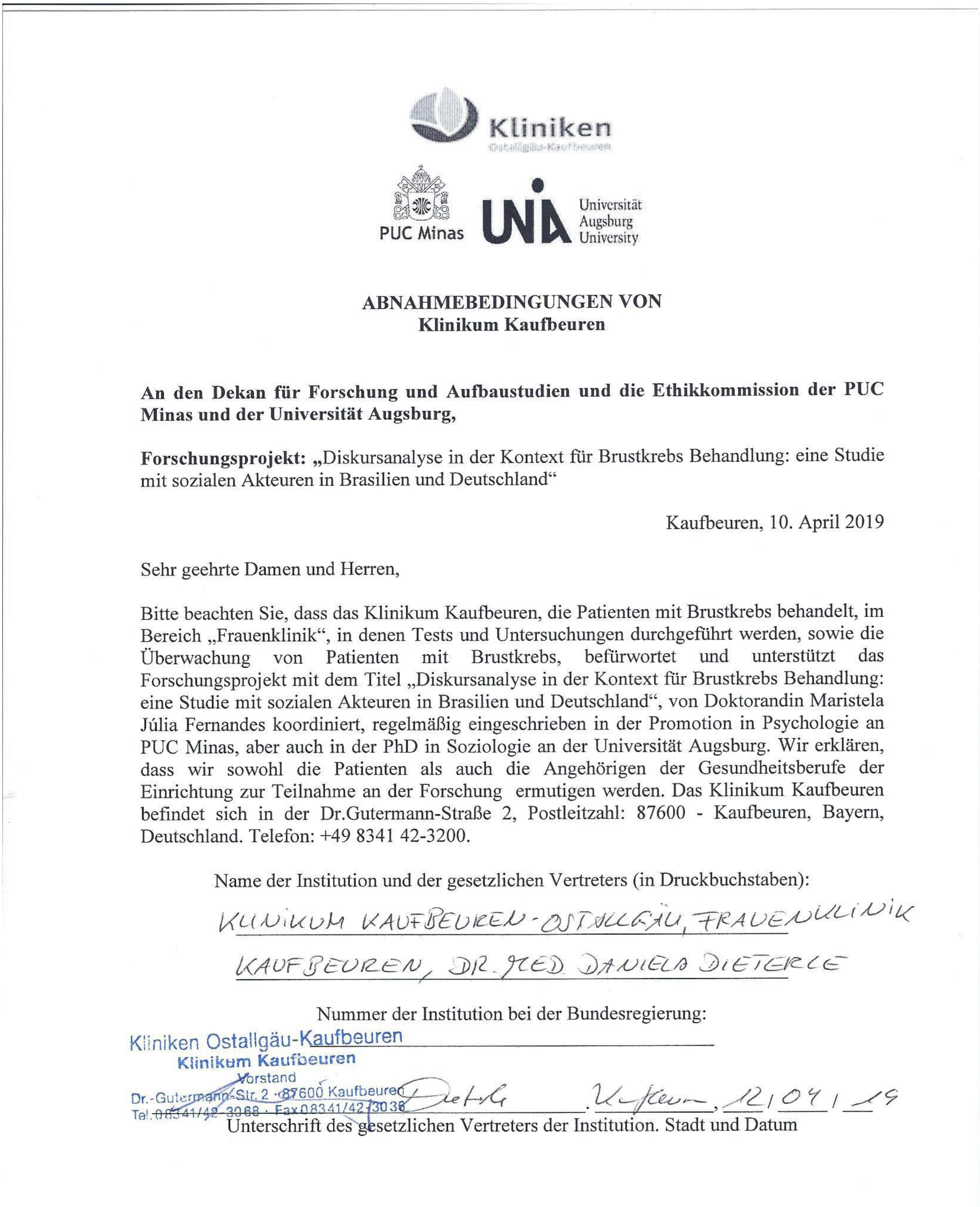
CETUS HOSPITAL-DIA ONCOLOGIA
RUA VINTE, Nº 90 - JARDIM BRASILIA
CEP: 32671-550 - BETIM / MG
CRM: 28.318

Belo Horizonte, 01 / Nov / 2016

Signature of the legal representative of the institution. City and Date

Dr. Charles A. J. de Pádua
Oncologia Clínica
CRM 30.464

APPENDIX B: Agreement Form for Hospital Kaufbeuren



Kliniken Ostallgäu-Kaufbeuren

PUC Minas

Universität Augsburg University

ABNAHMEBEDINGUNGEN VON
Klinikum Kaufbeuren

An den Dekan für Forschung und Aufbaustudien und die Ethikkommission der PUC Minas und der Universität Augsburg,

Forschungsprojekt: „Diskursanalyse in der Kontext für Brustkrebs Behandlung: eine Studie mit sozialen Akteuren in Brasilien und Deutschland"

Kaufbeuren, 10. April 2019

Sehr geehrte Damen und Herren,

Bitte beachten Sie, dass das Klinikum Kaufbeuren, die Patienten mit Brustkrebs behandelt, im Bereich „Frauenklinik", in denen Tests und Untersuchungen durchgeführt werden, sowie die Überwachung von Patienten mit Brustkrebs, befürwortet und unterstützt das Forschungsprojekt mit dem Titel „Diskursanalyse in der Kontext für Brustkrebs Behandlung: eine Studie mit sozialen Akteuren in Brasilien und Deutschland", von Doktorandin Maristela Júlia Fernandes koordiniert, regelmäßig eingeschrieben in der Promotion in Psychologie an PUC Minas, aber auch in der PhD in Soziologie an der Universität Augsburg. Wir erklären, dass wir sowohl die Patienten als auch die Angehörigen der Gesundheitsberufe der Einrichtung zur Teilnahme an der Forschung ermutigen werden. Das Klinikum Kaufbeuren befindet sich in der Dr.Gutermann-Straße 2, Postleitzahl: 87600 - Kaufbeuren, Bayern, Deutschland. Telefon: +49 8341 42-3200.

Name der Institution und der gesetzlichen Vertreters (in Druckbuchstaben):

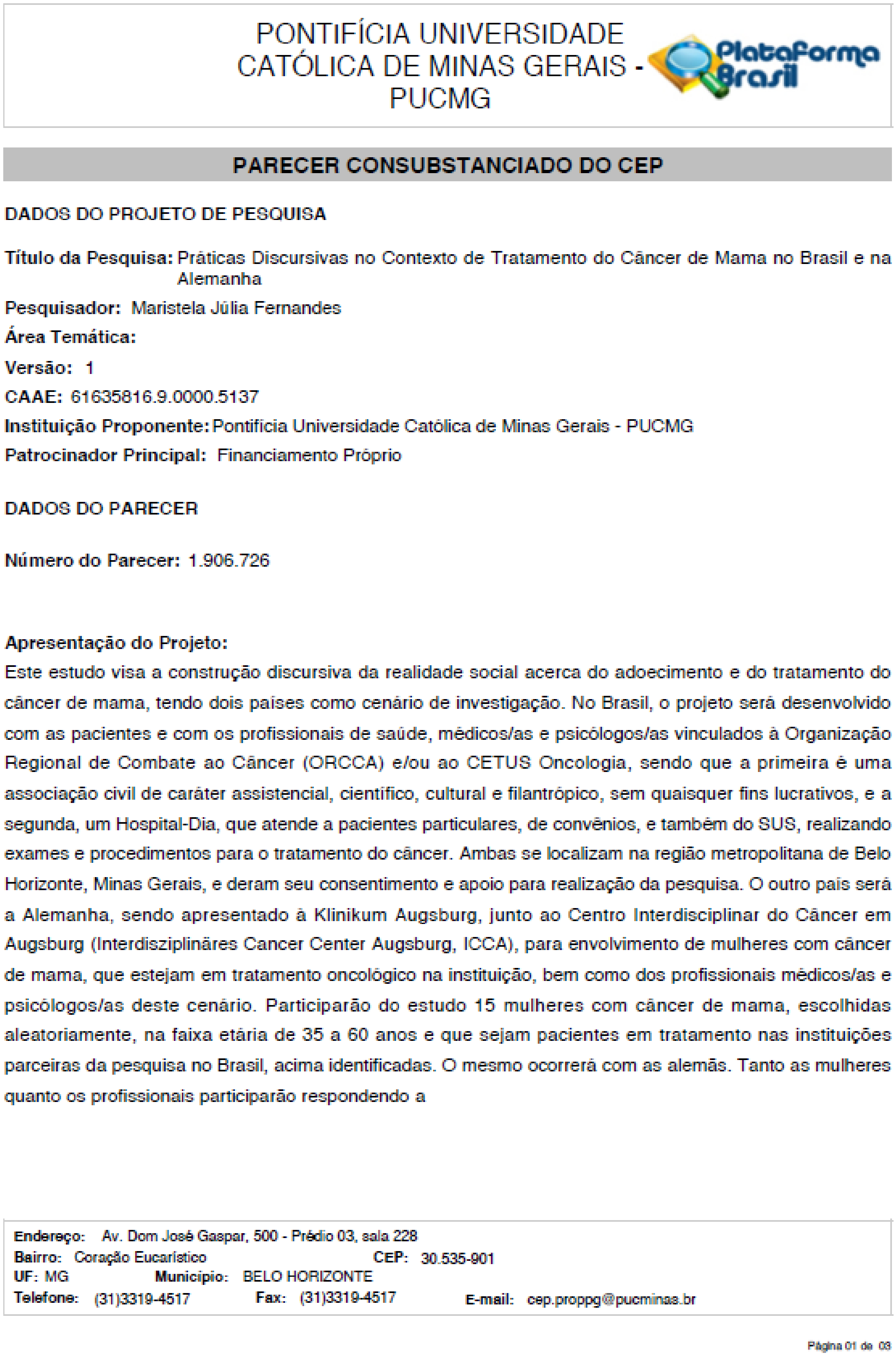
KLINIKUM KAUFBEUREN-OSTALLGÄU, FRAUENKLINIK
KAUFBEUREN, DR. MED. DANIELA DIETERLE

Nummer der Institution bei der Bundesregierung:

Kliniken Ostallgäu-Kaufbeuren
Klinikum Kaufbeuren
Vorstand
Dr.-Gutermann-Str. 2 · 87600 Kaufbeuren
Tel. 08341/42-3068 · Fax 08341/42-3036

Kaufbeuren, 12/04/19
Unterschrift des gesetzlichen Vertreters der Institution. Stadt und Datum

APPENDIX C: CEP Evaluation



PONTIFÍCIA UNIVERSIDADE
CATÓLICA DE MINAS GERAIS -
PUCMG

PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: Práticas Discursivas no Contexto de Tratamento do Câncer de Mama no Brasil e na Alemanha

Pesquisador: Maristela Júlia Fernandes

Área Temática:

Versão: 1

CAAE: 61635816.9.0000.5137

Instituição Proponente: Pontifícia Universidade Católica de Minas Gerais - PUCMG

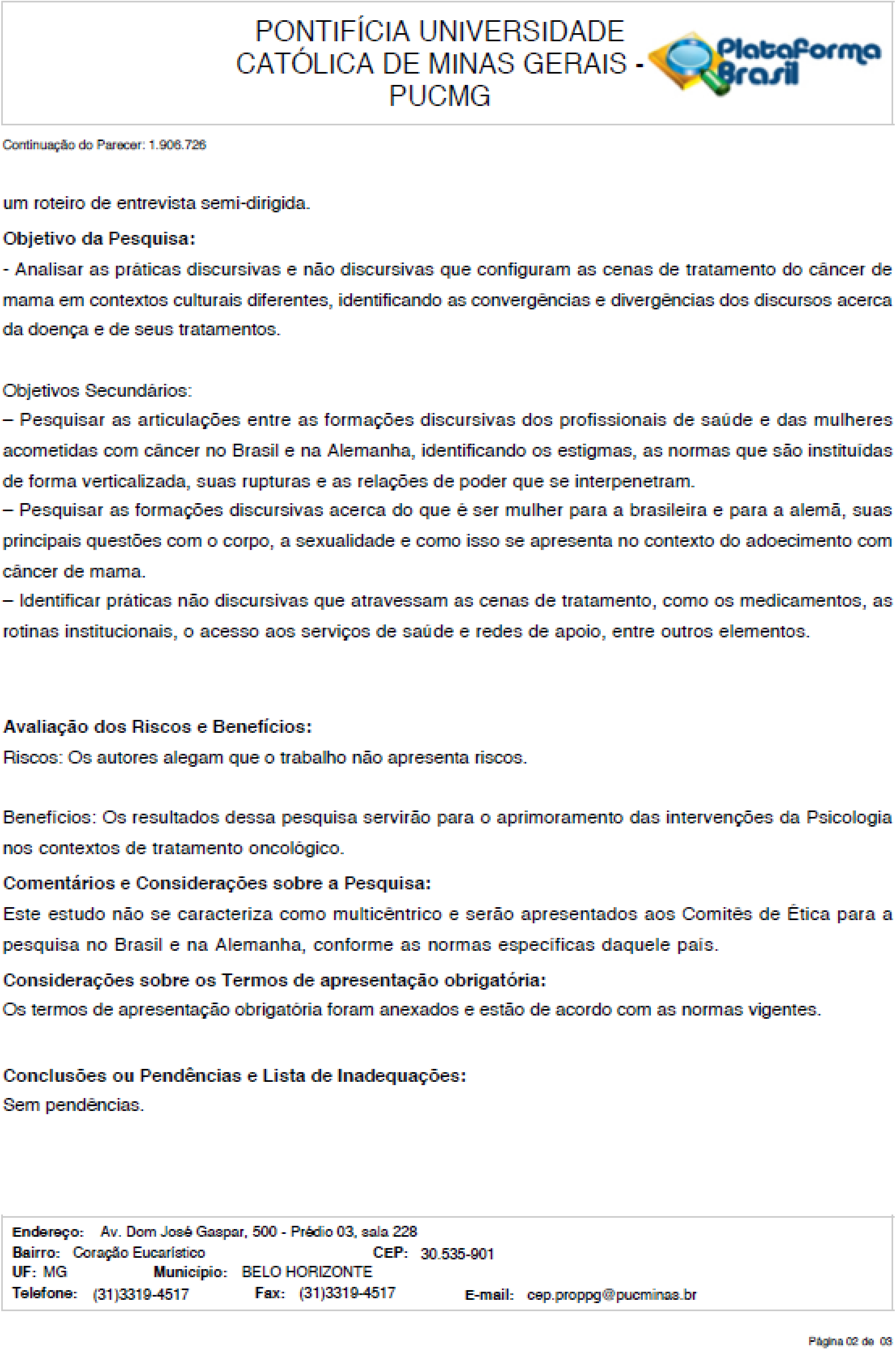
Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 1.906.726

Apresentação do Projeto:

Este estudo visa a construção discursiva da realidade social acerca do adoecimento e do tratamento do câncer de mama, tendo dois países como cenário de investigação. No Brasil, o projeto será desenvolvido com as pacientes e com os profissionais de saúde, médicos/as e psicólogos/as vinculados à Organização Regional de Combate ao Câncer (ORCCA) e/ou ao CETUS Oncologia, sendo que a primeira é uma associação civil de caráter assistencial, científico, cultural e filantrópico, sem quaisquer fins lucrativos, e a segunda, um Hospital-Dia, que atende a pacientes particulares, de convênios, e também do SUS, realizando exames e procedimentos para o tratamento do câncer. Ambas se localizam na região metropolitana de Belo Horizonte, Minas Gerais, e deram seu consentimento e apoio para realização da pesquisa. O outro país será a Alemanha, sendo apresentado à Klinikum Augsburg, junto ao Centro Interdisciplinar do Câncer em Augsburg (Interdisziplinäres Cancer Center Augsburg, ICCA), para envolvimento de mulheres com câncer de mama, que estejam em tratamento oncológico na instituição, bem como dos profissionais médicos/as e psicólogos/as deste cenário. Participarão do estudo 15 mulheres com câncer de mama, escolhidas aleatoriamente, na faixa etária de 35 a 60 anos e que sejam pacientes em tratamento nas instituições parceiras da pesquisa no Brasil, acima identificadas. O mesmo ocorrerá com as alemãs. Tanto as mulheres quanto os profissionais participarão respondendo a



um roteiro de entrevista semi-dirigida.

Objetivo da Pesquisa:

- Analisar as práticas discursivas e não discursivas que configuram as cenas de tratamento do câncer de mama em contextos culturais diferentes, identificando as convergências e divergências dos discursos acerca da doença e de seus tratamentos.

Objetivos Secundários:

– Pesquisar as articulações entre as formações discursivas dos profissionais de saúde e das mulheres acometidas com câncer no Brasil e na Alemanha, identificando os estigmas, as normas que são instituídas de forma verticalizada, suas rupturas e as relações de poder que se interpenetram.

– Pesquisar as formações discursivas acerca do que é ser mulher para a brasileira e para a alemã, suas principais questões com o corpo, a sexualidade e como isso se apresenta no contexto do adoecimento com câncer de mama.

– Identificar práticas não discursivas que atravessam as cenas de tratamento, como os medicamentos, as rotinas institucionais, o acesso aos serviços de saúde e redes de apoio, entre outros elementos.

Avaliação dos Riscos e Benefícios:

Riscos: Os autores alegam que o trabalho não apresenta riscos.

Benefícios: Os resultados dessa pesquisa servirão para o aprimoramento das intervenções da Psicologia nos contextos de tratamento oncológico.

Comentários e Considerações sobre a Pesquisa:

Este estudo não se caracteriza como multicêntrico e serão apresentados aos Comitês de Ética para a pesquisa no Brasil e na Alemanha, conforme as normas especificas daquele país.

Considerações sobre os Termos de apresentação obrigatória:

Os termos de apresentação obrigatória foram anexados e estão de acordo com as normas vigentes.

Conclusões ou Pendências e Lista de Inadequações:

Sem pendências.

]

PONTIFÍCIA UNIVERSIDADE
CATÓLICA DE MINAS GERAIS -
PUCMG

Continuação do Parecer: 1.906.726

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_817193.pdf	04/11/2016 00:06:05		Aceito
Projeto Detalhado / Brochura Investigador	Projeto_Final_Maristela.pdf	04/11/2016 00:03:06	Maristela Júlia Fernandes	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	Novo_Termo_Profissionais.pdf	04/11/2016 00:01:46	Maristela Júlia Fernandes	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	Novo_Termo_pacientes_mulheres.pdf	04/11/2016 00:01:27	Maristela Júlia Fernandes	Aceito
Declaração de Instituição e Infraestrutura	Orcca_Port_Assinada.pdf	02/11/2016 11:56:32	Maristela Júlia Fernandes	Aceito
Declaração de Instituição e Infraestrutura	Cetus_Port_Assinada.pdf	02/11/2016 11:56:07	Maristela Júlia Fernandes	Aceito
Folha de Rosto	Folha_Rosto_Assinada.pdf	02/11/2016 11:54:25	Maristela Júlia Fernandes	Aceito

Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

BELO HORIZONTE, 03 de Fevereiro de 2017

Assinado por:
CRISTIANA LEITE CARVALHO
(Coordenador)

Endereço: Av. Dom José Gaspar, 500 - Prédio 03, sala 228
Bairro: Coração Eucarístico **CEP:** 30.535-901
UF: MG **Município:** BELO HORIZONTE
Telefone: (31)3319-4517 **Fax:** (31)3319-4517 **E-mail:** cep.proppg@pucminas.br

Página 03 de 03

APPENDIX D: Consent Form Model for Brazil

INFORMED CONSENT TERM FOR PATIENTS

CEP Register Number.: CAEE 61635816.9.0000.5137
Opinion Number: 1.906.726

Project Title: Discursive Practices in the Context of Breast Cancer Treatment in Brazil and Germany

Dear Mrs,

You are being invited to take part in a Social Psychology research which aims to analyze the discursive and non-discursive practices which configure breast cancer treatment scenes in different cultural contexts, because it will involve patients and healthcare professionals in Brazil and in Germany.

You were selected because you are a patient linked to ORCCA (Regional Organization for the Fight Against Cancer) and/or to CETUS Oncology. Your participation in this study is will consist of receiving the visit from the researcher, who will ask you some questions and let you to talk about your experience with Breast Cancer. Data will be recorded in audio for better understanding of the subjects you approach in the semi-guided interview. **By this instrument, you also authorize the researcher to check your medical records for better understanding of your treatments.** The research does not offer identifiable risks.

Your participation is voluntary and of high importance and, by consequence, there will be no payment for taking part in this study. On the other hand, you will also have no expense.

Information obtained in this study will be confidential, your participation being granted secrecy when data are to be presented in scientific or educational publication, once the results are always presented as a group and not a person’s portrait. You may refuse to take part or to respond to any question, at any time, not existing any personal damage in your decision to do so.

All material collected during this research will stay under custody and responsibility of the researcher for the period of five (5) years and, after this time, it will be destroyed.

The results of this research will serve to the improvement of the Psychology interventions in the contexts of cancer treatment.

For every participant, in case of eventual damage occurring from the research, civil liability will be observed.

You will receive one copy of this term where you can find the telephone number and address of the responsible and may clear any doubt about the project and your participation, now or at any moment.

Researcher responsible: Maristela Júlia Fernandes, PUC Minas, student form the Doctoral Course in Psychology at PUC Minas. Professional Address: Rua do Rosário, s/n, Bairro Angola. Betim – MG. Telephone number: (31) 99988-9774.

This study was approved by the CEP – Research Ethics Committee involving Human Being of the Pontifical Catholic University of Minas Gerais, coordinated by Prof. Cristiana Leite Carvalho, who may be contacted in case of ethical questions, by the telephone (31) 3319-4517 or by e-mail cep.proppg@pucminas.br.

This term will be signed in two (02) counterparts of equal form and content.

Belo Horizonte, ____________ of 2017.

I agree by my own free will to participate in this study.

____

Participant's name (Please print name)

____ Date _______

Participant’s signature

I, **Maristela Júlia Fernandes**, hereby commit to fulfill all requirements and responsibilities granted to be in this term and thank you for your collaboration and trust.

____ Date _______

Researcher’s signature

APPENDIX E: Consent Form Model for Germany

Einwilligungserklärung zur Erhebung, Verarbeitung und Weitergabe personenbezogener Interviewdaten

Forschungsprojekt: „Diskursanalyse in der Kontext für Brustkrebs Behandlung: eine Studie mit sozialen Akteuren in Brasilien und Deutschland“
Durchführende Institution: Päpstlichen Katholische Universität (PUC) von Minas Gerais - Brasilien und Universität Augsburg – Germany
Projektleitung und Interviewerin: Doktorandin Frau Maristela Júlia Fernandes
Assistentin Interviews: Frau Lisa Hötzl
Interviewdatum:

Ich bin über das Vorgehen bei der Verschriftlichung, Datenspeicherung und Auswertung des von mir gegeben Interviews persönlich und mittels eines schriftlichen Handzettels informiert worden, der mir auch ausgehändigt wurde. Ich bin damit einverstanden, dass Sequenzen, die aus dem Zusammenhang genommen werden und damit nicht mit meiner Person in Verbindung gebracht werden können, als Material für wissenschaftliche Zwecke und die Weiterentwicklung der Forschung sowie für die Entwicklung Diskursanalyse in der Kontextgenutzt Behandlung von Brustkrebs.

Mir ist bewusst, dass die Teilnahme an diesem Interview freiwillig ist und ich zu jeder Zeit die Möglichkeit habe, das Interview abzubrechen und mein Einverständnis in eine Aufzeichnung und Transkription des Interviews zurückziehen, ohne dass mir dadurch irgendwelche Nachteile entstehen.

Unter diesen Bedingungen erkläre ich mich bereit, das Interview zu geben und bin damit einverstanden, dass es auf Band aufgenommen, abgetippt, anonymisiert, ausgewertet und in Sequenzen veröffentlicht wird.

Ich stimme auch zu, dass die Daten meiner Behandlung, die in der Krankenakte erfasst sind, vom Verfasser dieser Studie durchsucht und aufgezeichnet werden können. Ich bin mit damit einverstanden.

☐ja ☐nein

Vorname/Nachname (in Druckschrift)
____
Unterschrift ________________________________ Kaufbeuren, den
____

Ich bin damit einverstanden, dass das anonymisierte vollständige Transkript meines Interviews zur Archivierung und weiteren wissenschaftlichen Nutzung an eine Archivierungsstelle (z.B. PUC) übermittelt wird. Dort wird die Vollständigkeit der Anonymisierung der Interviews geprüft und falls erforderlich zusätzliche Maßnahmen zur Anonymisierung vorgenommen. Ich bin mit damit einverstanden.

Vorname/Nachname (in Druckschrift)
____

Unterschrift________________________________ Kaufbeuren, den
____

Informationen über den Umgang mit dem Interviewmaterial

Wir informieren Sie über das Forschungsprojekt, für das wir Sie gern interviewen möchten, und über unser Vorgehen. Der Datenschutz verlangt Ihre ausdrückliche und informierte Einwilligung, dass wir das Interview speichern und auswerten. Die verantwortliche Leitung des Forschungsprojektes „Diskursanalyse in der Kontext für Brustkrebs Behandlung: eine Studie mit sozialen Akteuren in Brasilien und Deutschland“ liegt bei Doktorandin Frau Maristela Júlia Fernandes, durchführende Institutions: Päpstlichen Katholische Universität von Minas Gerais - Brasilien und Universität Augsburg – Germany. Die Durchführung des Forschungsprojektes geschieht auf der Grundlage der Bestimmungen des Bundesdatenschutzgesetzes und hält den Ethik-Kodex der Deutschen Gesellschaft für Soziologie (http://www.soziologie.de/de/die-dgs/ethik/ethik-kodex.html) ein. Die Interviewerin unterliegt der Schweigepflicht und ist auf das Datengeheimnis verpflichtet.

Das Forschungsprojekt dient allein wissenschaftlichen Zwecken. Wir sichern Ihnen folgendes Verfahren zu, damit Ihre Angaben nicht mit Ihrer Person in Verbindung gebracht werden können:

- Wir gehen sorgfältig mit dem Erzählten um: Wir nehmen das Gespräch auf Band auf. Das Band wird abgetippt und anschließend gelöscht. Auch die Abschrift (Transkript) können Sie erhalten.
- Wir anonymisieren das Transkript, d.h. wir verändern alle Personen-, Orts-, Straßennamen, sowie alle persönlichen Angaben wie z.B. Alter, Beruf. Nicht anonymisiert wird aus Forschungsüberlegungen der Studiengang, nicht bekannt gegeben wird die untersuchte Krankehaus.
- Ihr Name und Ihre E-Mail-Adresse werden am Ende des Projektes in unseren Unterlagen gelöscht, so dass lediglich das anonymisierte Transkript existiert. Die von Ihnen unterschriebene Erklärung zur Einwilligung in die Auswertung wird in einem gesonderten Ordner an einer gesicherten und nur der Projektleitung zugänglichen Stelle (bzw. Datentreuhänder) aufbewahrt. Sie dient lediglich dazu, bei einer Überprüfung durch den Datenschutzbeauftragten nachweisen zu können, dass Sie mit der Auswertung einverstanden sind. Sie kann mit Ihrem Interview nicht mehr in Verbindung gebracht werden.
- Das anonymisierte vollständige Transkript meines Interviews wird zur Archivierung und weiteren wissenschaftlichen Nutzung an eine Archivierungsstelle (z.B. PUC) übermittelt wird und dort aufbewahrt und zur Verfügung gestellt, wenn das Einverständnis der/des Interviewten vorliegt.

Die Datenschutzbestimmungen verlangen auch, dass wir Sie noch einmal ausdrücklich darauf hinweisen, dass aus einer Nichtteilnahme keine Nachteile entstehen. Sie können Antworten auch bei einzelnen Fragen verweigern. Auch die Einwilligung ist freiwillig und kann jederzeit von Ihnen widerrufen und die Löschung des Interviews von Ihnen verlangt werden.

APPENDIX F: Questionnaire Model for Brazil

Script for Semi-Guided Interview with Patients

Name: ____

Interview Date: ____/____/______

I) Personal and Socio-Demographic Data

1) Age: _____ yers old.
2) Birth date: ....../....../.......
3) Marital Status:

( ) 1. Single ( ) 2. Married ( ) 3. Living as married

( ) 5. Widower ( ) 4. Separated / Divorced

4) Lives with a companion? 1. ( ) Yes 2. ( ) No (if you marke this option, please specify who do you live with_____________________________________
5) Do you have children? 1.( ) Yes 2.( ) No
6) **If yes,** how many children? __________________
7) Are you working nowadays? 1.( ) Yes 2.( ) No 3. ( ) yes, but I'm under medical license for my medical treatment
8) Education level: ____
9) **If you work:** What is your profession? ____
10) What is your family income? ( )1 - 2 minimum wages ( )3 - 4 minimum wages ( )5 or more minimum wages
11) Who is the main responsible for the family income?

( ) Me myself ( ) Spouse/Partner ( ) Others

II) Questions:

1) How did you get to know you had breast cancer?

2) Did you share your diagnosis with anyone (family and friends, for example?)
   a) If yes, what was their reception like?

   b) If no, what made you not share?

3) Which treatments have you been submitted to since the diagnosis?

4) Which professionals you have relied on during treatment? What is your relation like with every one of them?

5) Generally speaking, how do you notice the relation of women with their own bodies in your country?

6) Do you think breast cancer changes the way women see themselves?

7) Did you notice any changes in your body? If so, which?

8) How have you felt about your body currently?

9) What were or have been your greater difficulties since you got to know you had cancer?

APPENDIX G: Questionnaire Model for Germany

Formular für den Fragenkatalog (Semi-Guided Interview) mit dem Patienten

Name: ____

Datum für das Interview: ____/____/______

I) Persönliche Daten

1) Alter: _____ Jahre.

2) Geburtsdatum:....../....../............

3) Familienstand: ( ) 1. Ledig ( ) 2. Verheiratet ( ) 3. Liiert
( ) 4. Verwitwet ( ) 5. Geschieden

4) Leben Sie mit jemandem zusammen? 1. ( ) Ja 2. ( ) Nein
(**Wenn ja**, mit wem leben Sie zusammen) ____________________________

5) Haben Sie Kinder? 1.( ) Ja 2.( ) Nein
Wenn ja, wieviele Kinder haben Sie und welchen Alters?
____

6) Arbeiten Sie aktuell? 1.( ) Ja 2.( ) Nein 3. ( ) Ja, aber ich bin im Krankenstand für meine medizinische Behandlung.

7) Berufliche Ausbildung:
____

8) **Falls Sie arbeiten:** Was ist Ihr Beruf?
____

9) Wie hoch ist Ihr familiäres Einkommen pro Monat?
( ) 1000 – 2000 Euro ( ) 2000 – 3000 Euro ( ) oder 4000 Euro oder mehr.

10) Wer ist der Hauptverdiener der Familie?
( ) Ich ( ) (Ehe) Partner ( ) Andere___________________

II) Fragen:

1) Wie haben Sie erfahren, dass Sie Brustkrebs haben?

2) Haben Sie Ihre Diagnose jemandem mitgeteilt ? (Familie und Freunden, zum Beispiel?)

a) **Wenn ja**, wie war ihre Reaktion?
b) **Wenn nein**, warum haben Sie es niemandem mitgeteilt?

3) Welche Behandlungen haben Sie seit der Diagnose bekommen?

4) Welchen Fachkräften haben Sie sich während der Behandlung anvertraut? Wie ist Ihr Verhältnis mit jedem von ihnen?

5) Denken Sie, dass der Brustkrebs ihre Sicht des Lebens ändert?

6) Wie stehen die Frauen in Deutschland Ihrer Meinung nach generell zu ihrem Körper? Achten sie auf sich ? Sind sie eitel? Machen sie Sport oder Diäten? Im Allgemeinen es ist für den Frauen ihre Figur wichtig oder nicht?

7) Haben Sie während der Behandlung Änderungen in Ihrem Körper festgestellt? **Wenn ja**, welche?

8) Wie fühlen Sie sich aktuell mit Ihrem Körper?

9) Was war für Sie am schlimmsten/schwierigsten seit Sie Krebs haben?

10) Was können Sie mir noch erzählen über Ihre Krankheit oder sich selbst, was ich nicht gefragt habe?

APPENDIX H: Data Form Model for Brazil

Patient Treatment Datasheet

Name: ____

Datasheet start date: ____/____/______

1) Which type of Cancer and Phase of the Disease?
   ____

2) Time of diagnosis ? ____

3) Have you ever operated this type of cancer?

   1.( )Yes 2.( )No

4) If you operated, which surgeries were they?
   ____

5) Did you perform any mammary reconstruction? If yes, when?
   ____

6) Any chemotherapy? 1.( )Yes 2.( )No How many sessions?
   ____

7) Radioterapy? 1.( )Yes 2.( )No How many sessions?
   ____

8) Any medicaments?

   ____

   ____

9) Is there any breast cancer history in the family? 1.( )Yes 2. ( )No

APPENDIX I: Data Form Model for Germany

Datenblatt zur Patientenbehandlung

Name: ____

Erstellungsdatum: ____/____/______

1) Welche Art von Krebs und in welchem Stadium der Erkrankung wurde die Diagnose gestellt?____

2) Diagnosezeit: ____

3) Es wurde für den Krebs in Frage eine Operation durchgeführt?

1.( )Ja 2.( )Nein

4) **Wenn ja**, welche Art von Operation?

____

5) Es wurde eine Brustrekonstruktion Verfahren getan? **Wenn ja**, wann?

____

6) Chemotherapien ? 1.( ) Ja 2.( ) Nein

Wieviele? ____

7) Strahlentherapie? 1.( ) Ja 2.( )Nein

Wieviele? ____

8) Welche Medikamente?

____

____

9) Gab es bereits einen Brustkrebs Fall in der Familie? 1. ( ) Ja 2. ( ) Nein

____