cadernos pagu (64), 2022:e226401
ISSN 1809-4449

ARTIGO

The Dual Production of Bodies: Aging, Illness and Care in the Daily Life of a Family*

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Abstract

December 2018 marked 5 years that Leonor had been taking care of her elderly, blind, deaf, toothless mother, who also had cancer in one of her kidneys and advanced Alzheimer's. Dona Carmen's aging was absorbed to the daily life, body and mind of her daughter and caregiver Leonor, who developed a genital prolapse, tendinitis and depression due to the work of care combined with domestic work. In this text I present how the relationship of care between mother and daughter, elderly woman, and caregiver, overlap in daily life and produce strength and vulnerability. By describing the life of these women, I show the process of co-production of bodies through the duality of aging and illness in connection with a heterogeneous set of illnesses that accumulate with the passage of years. I also analyze the co-production of bodies in relation to broader social processes and temporalities.

Keywords: Care, Daily Life, Family, Domestic Work, Aging.

* Received on 06 April 2020, accepted on 10 June 2021. Between 2018 and 2019 I discussed this study at various times in Brazil, Portugal, England and Holland. Therefore, I am grateful to the questions and comments from Álvaro Molina and Felipe Szabzon; Graham Willis, Pedro Loureiro, Rachell Sánchez-Rivera, Martijn Oosterbaan, Yvon van der Pijl, Sara Koenders, Maria Manuel Quintela, Marta Maia, Regina Facchini, Carolina Branco de Castro Ferreira, Silvia Aguião, Patrícia Birman, Carly Machado, Adriana Fernandes, Mariana Ferreira and the members of the research group Distúrbio (UERJ/UFRRJ), Maria Hermínia Tavares de Almeida and all the members of IPP/CEBRAP. I would also like to thank FAPESP for the financing that allowed this work. Process: 2018/15928-2 and 2019/25691-2. Translated by Jeffrey Hoff.

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http://dx.doi.org/10.1590/18094449202200640001

Introduction

In December 2018 Leonor had completed five years serving as the sole person responsible for caring for her elderly and ill mother. When Dona Carmen came to her daughter's home in 2013 at the age of 80, she had been diagnosed with severe anemia, due to poor treatment she had received from her youngest son, who until then was her caregiver. In addition to anemia, Dona Carmen had advanced cataracts, partial deafness, was missing all of her teeth, had cancer of the gums, progressive Alzheimer's disease, diabetes and high blood pressure. In these years, Dona Carmen's aging was incorporated to the daily life, body and mind of her daughter and caregiver Leonor, who was also aging. Due to the excess work, which was the consequence of the overlapping of caregiving activities with domestic tasks, Leonor had developed tendinitis in her arms, genital prolapse and *depression*[1][2]. Less than discussing care through abstract categories, in this text I will examine Leonor's experience in caring for her mother, considering care for the elderly as a concrete problem to be faced in the daily life of this family (Mol; Moser; Pols, 2010; Han, 2012; Bellacasa, 2017).

I began the fieldwork in the popular housing occupation[3] where Leonor lived in 2010. In 2013, the year that the daughter went to get her mother to have her come live with her, I had already been visiting Leonor's home. I had become her friend and mainly a witness of the situations that she lived through[4]. Thus, I was able to accompany the immediate transformations that the arrival of Dona Carmen instilled in the life of her daughter, the effects of the caregiving relations and how the attrition produced over time were inscribed in the bodies and minds of these women. While observing these issues, it was the work of Kathleen Woodward (2012) that warned me of the "scandalous public secret of daily life" (2012:23), which is the relationship between the elderly and their caregivers. Critical of studies about aging that isolate the fragilized elderly from those who exercise care, Woodward invites us to not repeat the error of ignoring the experience of the caregivers. While Woodward articulates class, race, gender, generation and international immigration to analyze labor relations among elderly whites (in the US and Israel) who hire non-white women caregivers (from Jamaica or the Philippines), I propose discussing the complexity of these relations of care in a low income family in which the obligations of the daughter to her mother overlap that of caretaker for the elderly and ill, as well as domestic work and informal paid work with care activities. In other words, I will discuss effects that the relationship of care imposes on the life of the caregiver, which is aggravated when this person is also a family relation.

Different from studies that examine relations of care within low income families and focus on the abandonment of the elderly or the mentally ill by their families (Biehl, 2005; Povinelli, 2011), or from studies that discuss networks of solidarity and sharing of care amid precarity (Livingston, 2006; Fernandes, 2017; Fonseca; Fietz, 2018), what I present is the process that led Leonor to become the sole person responsible, among four siblings, for the care of her mother, as well as the effects of this responsibility on Leonor's daily life. To become the sole person responsible does not mean that Leonor had been abandoned by her family members or that there were not solidarities among members of her family or friends. To the contrary, abandonment and solidarity coexist and can be considered in specific situations. However, when I affirm that Leonor became the sole person responsible for her elderly and ill mother, what I have in mind are the "acts of care" (Kleinman, 2015), such as the physical acts of bathing, feeding, putting to sleep, controlling medication, combing hair, and helping to get up; activities that were done exclusively by Leonor for the 5 years

[1] Terms in italics are those used by Leonor or words from a foreign language. The terms between quotation marks are citations from texts, and are accompanied by a bibliographic reference.

[2] Leonor used the term *depression* to explain her emotional state, although she had not received a medical diagnosis.

[3] Popular housing occupation refers to the invasion of an abandoned public building and its transformation into housing for low income families. The expression is commonly used in the universe of occupations in Rio de Janeiro.

[4] In 2010 I began work as a technical support grantee (CNPq) for the study "Territórios, fronteiras e processos identitários: as comunidades e seus direitos" (2009-2014, CNPq) coordinated by Dra. Patrícia Birman (UERJ). From 2013 to 2015 and from 2016 to 2018 I made constant visits to Leonor to accompany her daily life. The processes that allowed me to enter Leonor's home and made me her friend and witness were described in Pierobon (2018). The research methodologies used for this article were field work, recorded interviews, cell phone conversations and messages exchanged on WhatsApp.

that I address in this text. To work with this specific relationship of care allows us to see how strength and vulnerability are coproduced in this process.

By accompanying Leonor's daily care for her mother, other themes appear to be important and complexify this relationship. As Veena Das (2015a) affirmed, the history of illness and of the ill are interlinked to the history of family relations. These histories also tell us of the tracks left by healthcare institutions and policies over the years. Far from presenting the experiences with care through a linear narrative, I will work with different temporalities that are part of Leonor's present and are "embedded" (Das, 2007) in the relation of care. With the concept of "duress[5]" (Stoler, 2016), I will discuss how healthcare policies and institutions have been inscribed over the years in the bodies and minds of Dona Carmen and Leonor and the importance of these inscriptions when we analyze the daily practices of care in the present. Following this reasoning, the bodies of these women will we considered as "political bodies" (Protevi, 2009), that is, bodies that have history, bodies whose experience is anchored in specific modulations and are shaped in the encounters with policies and institutions. It is in these encounters between bodies, family, policies, and institutions that the dichotomy between the public and private dissolves (Han, 2012; Das, 2015a).

As I introduced above, the histories of illnesses and the ill also speak to us of the histories of family. These, in turn, are entangled with relations of care and are frequently carried from the past to the present. Leonor's family histories were troubled, and they often spoke of betrayals (Pierobon, 2021). However, the past experiences of family betrayals, as Veena Das (2007) examined, constitute the relations of daily life. Working with the way that women remade their lives after the experience of the Partition of India and Pakistan in 1947, Das invites us to look at how these betrayals were absorbed to daily life. In more recent studies in which Das analyzes processes of illness within low-income families on the periphery of New Delhi (2015a) she discusses how certain events are not absorbed and make daily life unsupportable. Much of the violence experienced by Leonor within her family was incorporated to her daily life. Others, however, disturb her. It is one of these events that were not absorbed and continues to be disturbing, or, in the words of Janet Carsten (2007), it is one of these "ghosts of memory" that torment her relations that I will consider below, showing how they are interlaced with dynamics of care.

Before continuing, I emphasize that in Brazil care for the elderly is not treated as an issue of public health, but as a domestic problem[6]. As Helena Hirata and Guita Debert (2016) noted, the issues about care must be discussed publicly and treated as a political issue. We know that the Brazilian population has been aging rapidly and according to the Brazilian census agency, IBGE (2010), will triple by 2050 and reach 66.5 million people. The last Pesquisa Nacional de Saúde (IBGE, 2013) shows that more than 80% of the elderly who require care receive this "help" exclusively from family members[7]. Although the study does not include the variable of gender, it is not difficult to imagine that it is mostly women who care for elderly family members. Supported by the authors mentioned above, I think that we know little about how low income populations are aging, becoming ill and being cared for in their daily practices. In this context, I affirm that we know even less about how care concretely affects the life of caregivers, especially those who are family

[5] Ann Laura Stoler (2016) developed the concept of "duress" to think of how colonial history continues to influence the present, acting on and impacting relations. In Stoler's words: "duress, then, is neither a thing nor an organizing principle so much as a relation to a condition, a pressure exerted, a troubled condition borne in the body, a force exercised on muscles and mind. It may bear no immediately visible sign or, alternatively, it may manifest in a weakened constitution and attenuated capacity to bear its weight. Duress is tethered to time but rarely in any predictable way. It may be a response to relentless force, to the quickened pacing of pressure, to intensified or arbitrary inflictions that reduce expectations and stamina. Duress rarely calls out its name. Often it is a mute condition of constraint. Legally it does something else. To claim to be "under duress" in a court of law does not absolve one of a crime or exonerate the fact of one. On the contrary, it admits a culpability—a condition induced by illegitimate pressure. But it is productive, too, of a diminished, burned-out will not to succumb, when one is stripped of the wherewithal to have acted differently or better" (Stoler, 2016:7).

[6] For a discussion about how care was historically made invisible and treated as a domestic problem see, Laugier (2011, 2015). For an analysis about how for a long time care was of little intellectual interest see, Moll, Moser & Pols (2010). About the differences in care in countries with welfare state experiences and countries where care is treated as a domestic issue see, Fonseca and Fietz (2018).

[7] For a detailed analysis about care for the elderly surveyed by the Pesquisa Nacional de Saúde [National Health Study] (IBGE, 2013) see, Lima Costa et. al. (2017). The term "help" is used in the Pesquisa Nacional de Saúde.

members. Thus, this article is an attempt to consider what it means to make a life in in its more intimate forms without separating it from the public dimensions. To be able to expand discussions about care in daily life, Woodward (2012) affirms the importance of telling more biographical histories of the elderly and their caregivers and that these histories be extracted from concrete daily experience. It is following Woodward's provocation, therefore, that I describe Leonor's experience caring for her mother in an attempt to bring to the public domain issues that insist on being naturalized as private.

Duress

In 2013 Leonor took her mother to live with her in the popular occupation where she lives, located in the historic center of the city of Rio de Janeiro. As soon as Dona Carmen arrived, the first characteristics that I noticed were her physical and cognitive limitations caused by the advance of Alzheimer's disease, which were inseparable from her aging process. While these limitations appeared to me to complicate Leonor's daily activities, she gradually revealed to me the concrete problems that she faced: Dona Carmen's incomprehensible statements, the common evocations of her deceased parents, the uninterrupted requests to go to *her* house, the insomnia that gradually became common, her mother's attempts to masturbate, the times when Dona Carmen did not recognize her daughter and inverted the roles. There was also her difficulty to move around, the advance of urinary and fecal incontinence, partial deafness, the progressive cataract, the absence of teeth, the gum cancer, high blood pressure, anemia, and diabetes. Leonor had not lived with her mother for a few years due to Leonor's conflicts with Cleber, the brother responsible for caring for Dona Carmen before she came to Leonor's house. For this reason, Leonor had known little about how aging and senility had compromised her mother's body and mind. Day after day, she needed to understand the characteristics of Dona Carmen and they were being incorporated to Leonor's daily life – some more than others. Aging and Alzheimer's are continuous and each small change in her mother's body and her own required that Leonor become accustomed to the novelty.

By accompanying Leonor's daily life over the years, I was able to perceive that the dynamics of care became more complex when aging and senility combine with the effects of other illnesses. The absence of teeth and blindness were two of the characteristics present in Dona Carmen's body that left Leonor's daily life even more difficult. Curious about the process that led Dona Carmen to lose all her teeth and go blind, I asked Leonor to tell me what she knew about these processes, given that Dona Carmen was not able to tell these stories[8]. From what the daughter showed me to be a problem, I present below how certain diseases were year after year producing Dona Carmen's body and how the accumulation of these illnesses in this specific body had concrete effects in the present of the person who became responsible for care. To analyze marks found in the bodies of people based on the histories of the diseases that occur in different phases of life allows us to perceive how the country's inconsistent healthcare policies are present in bodies at the same time in which they become inheritances for later generations. It is in this sense that the bodies considered here are thought of as "political" (Protevi, 2009).

Let us turn to Dona Carmen's body. Dona Carmen lost her teeth and the ability to use dentures in a process that began in the late 1970s. When she was 45 to 50 years old, Dona Carmen had periodontitis and soon lost all her teeth. Without access to dental implants, she used dentures for more than 20 years, which caused atrophy of the gums, which in turn made it difficult for her to use dentures. Her dentures were discarded in 2014 when she developed cancer in what remained of her gums. Radiation therapy was also necessary, which burned part of her mouth, tongue, esophagus, as well as the gums and the dentures hurt the area affected. With the end of the radiation treatment, conducted through Brazil's federal public Single Healthcare System (SUS), Leonor sought dental implants through this system, without success. Since then, Dona Carmen does not use dentures. She is one of the 16 million Brazilians who have no teeth and is among the 77.7%

[8] Veena Das (2015a) tells us to pay attention to the statements of people classified as "mad" or "incapacitated". I tried to conduct this exercise with Dona Carmen and in future work I intend to address this problem. However, it was not possible for Dona Carmen to tell me about her processes of illness in a way that I could understand them.

of those people without teeth who do not use dental protheses (IBGE, 2013). According to the report of the Pesquisa Nacional de Saúde (IBGE, 2013) the group most affected by the absence of teeth are elderly women.

Periodontitis is a bacterial infection that affects the gums. Moderate and grave levels of the diseases afflict 6.3% of Brazilian adults, and the poor, black and male population is the most affected (PNSB, 2012). Although I am concerned with the history of periodontitis in Dona Carmen's body and with the concrete effects that the absence of teeth caused in Leonor's daily life, I present the statistical data to show that this problem affects millions of Brazilians, and therefore is not only a domestic problem. To the contrary, the absence of teeth is a public health problem that affects people differentially by class, race, and gender. Periodontitis is an infection considered easy to treat. Dona Carmen's teeth could have been saved if she had received odontological care and basic mouth hygiene instructions during her life.

The argument that I defend is that the loss of teeth from periodontitis can be seen as a form of duress (Stoler, 2016) of the healthcare policies inscribed in Dona Carmen's body. Considering Stoler's reflections (2016), I think that the loss of teeth caused by a bacterial infection that is easy to treat can be seen as an effect of the public policies existing at the time, which prevented her from receiving care from a dentist. Dona Carmen developed periodontitis in the late 1970s. In those years, the dictatorial government faced a grave financial crisis (1974-79) and public healthcare policies that had already been scarce were cutback even more (Vianna; Paim, 2016). Families like that of Dona Carmen – who got by on informal labor and did not have social security benefits – were profoundly affected because they were considered to be indigent by the Brazilian state and therefore did not have access to public healthcare institutions (Ponte; Nascimento, 2010). Unlike studies that analyze healthcare policies in the period of the military dictatorship based on their absence, I propose that we reconsider the question asked by Edson Telles and Vladmir Safatle: "O que resta da Ditadura?" [What is left of the dictatorship?] (2010), looking at how healthcare policies aimed at poor populations were implemented in that period, how they were productive in the formation of bodies and how they became an inheritance that continues operating in the processes of making a family in the present (Stoler, 2016; Han, 2012).

We now turn to another of the characteristics of Dona Carmen's body that Leonor highlighted as a complication in her daily life: blindness, which was provoked by a cataract. The first symptoms of the cataracts appeared in Dona Carmen's eyes in the mid-1990s. The military dictatorship had ended and with redemocratization SUS was created and the Organic Health Law was approved that determined that health was a universal right that is free of charge. The 1990s were also marked by a decentralization in public healthcare services from the federal level to the states and municipalities, simultaneously to support for the individualization of healthcare through the private sector (Biehl, 2005; Levcovitz et al., 2001). In practice, there were cuts in investments in public healthcare and this new configuration made it difficult for families to access the public system, even those who in the past had been attended by the healthcare institutions. Many families came to allocate their own scarce and needed resources to treat diseases (Biehl, 2005). It was during these political changes that Dona Carmen became elderly and Leonor became an adult woman. At this specific moment, Dona Carmen began to develop a cataract and could not access the public or private healthcare systems. But in this specific case, this duress caused by state policies was interlinked to family relations (Biehl, 2005; Das, 2015a).

Dona Carmen's husband died in the mid-1990s and she shared the home in the Zona Oeste of Rio de Janeiro with her youngest son, Cleber. Without money to pay for private surgery and without access to public healthcare institutions she was gradually losing her sight. Her oldest daughter suggested that she move to São Paulo, because she had contact with agents of the municipality who could facilitate access to surgery in the city. Dona Carmen went to São Paulo where she lived with her grandson since he had the best working conditions and could save his grandmother's retirement income so she could have surgery in the private system. But the grandson took his grandmother's money and was accused of treating her poorly. Without the surgery in the public or private system, Dona Carmen returned to live with Cleber in Rio de Janeiro, where she suffered physical aggressions and other poor treatment, which led Leonor to take her mother to live

with her. As soon as Dona Carmen reached her daughter's home in 2013, her daughter contacted the closest Family Clinic[9] and began the bureaucratic process for the cataract surgery under SUS. Exams found an advanced stage of cataracts in Dona Carmen's eyes and the probability of success in the surgery was low. For this reason, she was not placed on the SUS list for surgery. Year after year the cataracts in Dona Carmen's eyes advanced until she became blind.

A cataract makes the eye lens opaque, and a person gradually goes blind. Treatment requires a surgery that, according to the Ministry of Health, is simple and the success rates are 90%. The results of the Pesquisa Nacional de Saúde (IBGE, 2013) show that 31.9% of women have had cataracts and are the most vulnerable group. According to a report by the Brazilian Ophthalmology Council (2015), in 2015 350 thousand people became blind because of cataracts. However, there are no data about the social classes most affected by blindness from cataracts, but we can infer that the poor are those who are not able to have surgery and wind up going blind due to a common condition of aging, which is considered to be cheap and easy to resolve. Since in Brazil there is a direct association between social class and race, it is possible to imagine that the Black population is that which suffers most from blindness caused by cataracts.

By combining cataracts and periodontitis with the impossibility of treatment of these diseases in a single body we see how healthcare policies have overlapping durations and become present in the bodies of people (Stoler, 2016; Han, 2012). The fact that Dona Carmem does not receive adequate treatment, at the beginning of the cataract process, by the public healthcare system - that was taking its first steps under redemocratization - prevented the surgery from being conducted, even with the expansion of SUS in the decade of 2000. The periodontitis and gum atrophy are effects of healthcare policies during the military dictatorship that continue to act in the present of Dona Carmen. On the other hand, the treatment for mouth cancer conducted completely under SUS in 2014 and the inability to have surgery for dental implant surgery in the same system shows us the ambivalence of this public service in the production of life and vulnerabilities: she cured her mouth cancer, but it left her toothless. From this perspective, the illnesses are revealed as deeply social and political. By focusing on the temporalities of healthcare policies, and how various policies are inscribed in a single body and on inheritances for later generations, we can better understand how current healthcare policies produce a duress that is projected into the future. Before continuing, I highlight that 75% of Brazilian elderly only access SUS for treating and accompanying disease[10].

Inheritance

I would like to return to the idea that the country's healthcare policies and its discontinuities are present in the bodies of people while they also become inheritances for later generations. In other words, I will now discuss how the past continues to construct a present and a future beyond the duration of a human life (Han, 2015). Based on Ann Laura Stoler's (2016:7) idea that duress is not easily visible and identifiable, but is a "turbulent condition supported by the body", "a force exercised on muscles and the mind", I present how the characteristics produced over the years on Dona Carmen's body are making the body and mind of her daughter Leonor. Carmen's transformation from near blindness to complete blindness will be the theme that presents these issues, given that Dona Carmen's blindness is part of Leonor's daily life and requires specific care in different moments. However, when I describe the "acts of care" (Kleinman, 2015) it is impossible to isolate the advance of the cataracts from other processes that produce Dona Carmen's body, especially the progression of the Alzheimer's disease and its effects.

Not everything is expressed by verbal language, as Mol, Moser & Poll affirm (2010). These authors warn that by only emphasizing verbal language, we lose a large non-verbal component in daily care practices (2010:10). Following this reasoning, I describe two ethnographic scenes that I witnessed and reveal one of the functions of the daughter in the care for her mother: that of taking

[9] The Family Clinics are public healthcare clinics administered by the municipalities through SUS that offer basic healthcare to the population focused on primary care.

[10] Site consulted: https://www.saude.gov.br/noticias/agencia-saude/44451-estudo-aponta-que-75-dos-idosos-usam-apenas-o-sus Access: 01 Oct. 2020.

her to the bathroom. The first scene was in 2014 when Dona Carmen, although nearly blind, was able to guide herself through the house steering by lights and shadows. The second was in 2016, when she was completely blind. Although at first sight the "act of care" is the same, "taking mom to the bathroom", what I try to make evident is how the subtle differences between near blindness and complete blindness transformed Leonor's daily life, infiltrated her muscles and as we will see, her mind. I will present the scenes.

Even with the advance of Alzheimer's, Dona Carmen refused to urinate and defecate in geriatric diapers. By *holding her pee and poop*, when Leonor put diapers on her, other problems such as urinary infection arose. For this reason, Leonor made a point of taking her mother to the toilet, an act that is anchored in her "care ethic" (Laugier, 2015) that affirms: *going to the bathroom is one of the few pleasures that my mother has in life.* To avoid diapers and take her mother to the bathroom is linked to the cost of geriatric diapers for a domestic budget of one minimum wage per month[11]. Although nearly blind in 2014, Dona Carmen was able to guide herself through the house through lights and shadows. At that time, the muscles in her legs and arms had sufficient strength to support herself. Thus, when she wanted to go to the bathroom, Dona Carmen got up from where she was, and guided herself by the light that was always on in the bathroom, and walked by supporting herself on the table, sofa, or chair. That year "taking her mother to the bathroom" meant helping her sit correctly on the toilet, cleaning her, helping her to get up and washing her hands. Dona Carmen then walked back to where she was, but Leonor was always attentive in case she needed to help her when she lost her balance.

In 2016 Dona Carmen was blind, the effects of Alzheimer's disease advanced and the muscle strength in her legs and arms diminished. Blind, without strength and less cognitive capacity, the minimum autonomy of getting up and walking to the bathroom was interrupted. For Dona Carmen to be able to go to the bathroom, Leonor tried to take her in a sanitary chair. However, the chair was too old, the wheels did not work and maneuvering it in the small home was difficult. The easiest way that Leonor found was to serve as support for her mother during the route to the bathroom, even if Leonor was making most of the effort. Then, the daughter would take her mother back to the bed or sofa. At times, Leonor literally carried Dona Carmen. Day after day, year after year, the work of taking her mother to the bathroom began to be taxing on the body of the daughter who was also aging. This was one among the dozens of functions as caretaker. The accumulated work caused Leonor to slowly develop tendinitis in her arms and a genital prolapse.

I would like to reflect on Leonor's routine of taking her mother to the bathroom every day raising the paradox about the daily life developed by Veena Das (2015b; 2020). For Das, we researchers cannot suppose that ordinary life is something simple and that its elements are obvious and guaranteed. To the contrary, it is exactly habit, routine and repetition that guarantees life. The work of making life every day requires the repetition of cooking, cleaning, combing hair, taking to the bathroom. Beyond repetition, daily life, for Veena Das, is a place of doubt, skepticism, uncertainty, but also a place where ethical decisions are made daily. I add that the paradox of daily life is that it is produced precisely through routine, habit, a repetition of tasks that slowly accumulate, modifying bodies and minds. In this sense, daily life is habit and routine, but synchronically, it is the new being made in these small acts. The opacity in the eye lens that advances each day in Donna Carmen's eyes produces microwear on Leonor's muscles. Conducting life every day, like taking her mother to the bathroom, even if it is not something that stands out in daily life, is the place of potentiality of life, but also of the production of vulnerabilities.

This apparently small change in Dona Carmen's body reveals how healthcare policies have a duration, become inheritances for later generations and continue to act in the formation of bodies beyond a human life. To carry her mother to the bathroom does not only show us that domestic worlds are remade under economic pressures (Biehl, 2005; Han, 2012), but that the bodies of the elderly and caretakers are transformed in connection with the duress of previously existing

[11] In December 2013, the monthly wage in Brazil was 678,00 reals or approximately US$ 291 dollars. In December 2018, the minimum wage was 954,00 reais or approximately US$ 243 dollars. Sites consulted: http://www.idealsoftwares.com.br/indices/dolar2018.html, http://www.idealsoftwares.com.br/indices/dolar2013.html http://www.guiatrabalhista.com.br/guia/salario_minimo.htm. Access: 01 Oct. 2020.

healthcare policies. Here I return to Hirata and Debert (2016) who affirm that care for the elderly in Brazil is treated like a domestic problem. Therefore, it is family members who give themselves to caring for those who had their bodies debilitated irreversibly by diseases that are easily treated. The naturalization of the family as the place of care for their elderly members delegates a perverse inheritance that more sharply afflicts low-income families and especially women[12]. Care as an activity exercised exclusively by the family becomes even more arduous when it is overlapped by domestic work.

Responsibility

In this part of the article I reflect on how women become responsible for caring for the elderly in their families, without forgetting that these same women are responsible for caring for children and often grandchildren[13]. French philosopher Laugier (2011; 2015) affirms that care was defined, accepted, and naturalized as a moral value defined as "female". The moral division of labor historically disqualified and made invisible the various domestic labors, removing their moral and political importance (McClintock, 2010; Mol; Moser; Pols, 2010; Laugier, 2015; Bellacasa, 2017). The work of care is one of the responsibilities attributed to domestic life that falls with greater weight on women who, in turn, must deal with this responsibility. As Veena Das (2015a) writes, we should not naturalize the responsibility that one person assumes in relation to another. To the contrary, efforts should be made to perceive how individual histories and subjectivities connect with the broader social logic that insists on making women responsible for care.

In the first part of the article I briefly showed some of the movements of Dona Carmen between the homes of her children and grandchildren until she remained at Leonor's house. By reviewing the motives that led to these changes of address we see the ambivalence between care and poor treatment, dedication and negligence, affection and abandonment. To accompany these movements means to denaturalize Leonor's role as caregiver to understand the processes that caused her to become the sole person responsible for her elderly and ill mother. However, in daily life there are other forms of assuming responsibility for care for another and below I will present some of the entanglements of these practices with daily work.

When Dona Carmen arrived at Leonor's house, in addition to all the illnesses that I presented at the beginning of the article, she had lice in her hair and pains in her ribs which had Leonor suspect that she had suffered physical abuse from Cleber. The problems of health and illness that Leonor decided to confront to prolong her mother's life with the best quality and least suffering possible were, therefore, enormous. By means of her networks of family and friends she obtained a sanitary chair and a wheelchair; she took Dona Carmen to public medical clinics and hospitals countless times; fought with state agents to initiate processes for radiation therapy, cataract surgery, and dental implants. Leonor did not accept the denials of access to some healthcare services and she turned to public defenders and hospital ombudsmen. Although most of the time she was alone, she had a small network of solidarity, in which I was included, which was important for providing Leonor access to some of these actions. Even Dona Carmen had solidarity from friends she made when she attended an Evangelical church. These women, whenever possible, took geriatric diapers to their ill friend and Leonor saved them to put on her mother when she slept or left the house.

In daily life, I could accompany the diet carefully prepared by Leonor to confront her mother's anemia, diabetes, hypertension…the choice of fruits, vegetables, grains, products of animal origin, as well as their combinations for each specific situation were always thought of based on the knowledge that Leonor acquired in life, but also from research on the internet, conversations with doctors, and by exchanging experiences with other people in the same situation. Over the years, Leonor acquired an expertise about medications, food and about the best hospitals, doctors, and

[12] I would like to thank Regina Facchini for the comments to the text and for calling my attention to this process.

[13] Due to space limitations and the issue proposed in this article, I am not able to go further into the relationship of care of Leonor for her children and grandchildren. However, Leonor's family relations, which include caring for her children and grandchildren, appear in different chapters of my thesis (Pierobon, 2018). For a discussion about care for children in the lower classes see the work of Fernandes, 2017.

nurses in her region. Her choices were deeply moral, to the degree to which she would always serve good food and choose a good doctor, and a good hospital with the objective of doing good for her mother.

For Dona Carmen to be able to eat without chewing, Leonor cooked the food and then put it in a blender to make it creamy. For example, Leonor would cook and then blend beef, and then carrots with lentils, then rice, *batata baroa* [similar to a turnip], all separately. For five years, every day, and at all meals, Leonor would repeat the same procedure. The action of placing food in the blender was a function of care that combined with the domestic work of cooking. By means of this small "act of care" (Kleinman, 2015) we see how domestic work and care coexist and accumulate in daily life. However, Leonor did not take the same procedures for herself, in part, because she had teeth and could chew her foods. Due to the limited resources, some foods were only eaten by Dona Carmen, such as salmon, ginseng, chia, and kiwi. In her ethic of responsibility, Leonor produced an hierarchization of bodies in which her mother's body had priorities to receive certain foods and with them, nutritional properties.

The dynamics of care caused Leonor to dedicate her life to this function: feeding her mother three to four times a day, taking her to the bathroom countless times, bathing her, putting her to sleep, arranging doctor's visits and medications. All of these activities were incorporated to her daily life and overlapped her domestic tasks that included going to the supermarket, cooking, cleaning the house, caring for grandchildren, caring for a dog. I would like to emphasize that all these activities were conducted on the fourth floor of a building without elevators. This meant that each time Leonor left her home, she had to go down and up four flights of stairs by foot, often carrying goods in her arms. The potable water supply was precarious in her home, so carrying heavy five- or ten-liter water bottles was also one of the jobs necessary to make her domestic life viable.

If Dona Carmen's presence gradually caused Leonor to incorporate the limitations of her mother's body and produce new domestic dynamics, this meant that other activities conducted by Leonor were abandoned. She no longer took paid jobs caring for elderly people in middle class homes, which is very common for low-income women. She also stopped her paid work cleaning homes by the day, she stopped selling tapiocas in the streets of the region, and she no longer distributed pamphlets for unions and political parties. Her main source of income came to be the Elderly Assistance Benefit [14] received by Dona Carmen, of one minimum wage, which would be cut upon her death. To earn some extra money, but irregularly, Leonor began to crochet and sell clothes, she sold meals at the door of her house and at times she cared for the children of other women who lived or worked in the region. Both came to live intensely within the home, a place where Leonor did the domestic work, the care and informal paid work. Upon glimpsing the future, Leonor intended to receive the Elderly Assistance Benefit when she turned 65, in 2023, a benefit that is in risk given recent policies in the country.

Nevertheless, it was not only paid activities that Leonor was abandoning. With the passage of time, little by little I saw Leonor give up leisure activities and those that improved the quality of life of her body: she stopped her swimming classes at a social project close to her house; she stopped walking in the park with her friends; she stopped going to restaurants and bars in the region; she stopped visiting friends who lived in distant neighborhoods. In her new condition, Leonor came to see her daily life as a form of confinement: *I live in confinement.* Although Leonor did not accept this condition and made every possible effort to maintain activities outside the home, the responsibility for caring for her mother impeded the continuity of many of her actions.

To observe Leonor's daily life had me think of the work regiment of someone who cares for a person with advanced Alzheimer's, but who is also blind, toothless and has other illnesses. This is to say that the person with the disease is incapable of conducting tasks alone, even simple personal care like face washing when waking up. The caretaker is responsible for all the tasks, responsibilities and obligations for that ill person, which is even more complicated when the caretaker is a family member, is the sole person responsible for care, and is also old and low income. In this sense, the

[14] The Benefício Assistencial ao Idoso [Elderly Assistance Benefit] is a guaranteed minimum wage available to people older than 65 whose family income is lower than ¼ of a minimum wage. See: https://www.inss.gov.br/beneficios/beneficio-assistencia-a-pessoa-com-deficiencia-bpc/beneficio-assistencial-ao-idoso/. Access: 01 Oct. 2020.

care for a home in daily life coexists with the care for the ill person and with the informal paid work. These conditions force the caretaker to be active without stop, often having to work through the night, without being able to rest or share any task.

Before continuing, I would like to emphasize that for Leonor, it was unthinkable to put Dona Carmen in a nursing home. Leonor had heard rumors of poor treatment at nursing homes, and had experienced difficult situations in public healthcare institutions[15]. Based on these experiences, she understood that Dona Carmen would not receive the care considered ideal for her mother. At the same time, Leonor understood nursing homes to be places where families abandon their elderly. Thus, Leonor constructed a self-responsibility for care for her mother in an aversion to abandonment that, in her case, included the accusation that her brothers abandoned Dona Carmen. If the sons abandoned their own mother, Leonor would fulfill this function, with her words: *I would never abandon my mother, my family.* As I described above, 80% of the elderly are cared for by members of their own families. What is clear is the weight that these activities of care impose on the lives of women.

Memory

The history of illness and of the ill speak to us of the histories of family. I would like to consider this formulation by Veena Das (2015a) to present an important element found in the care practices exercised by Leonor: the memories of pain present in relations with family members. If, I used the idea of duress (Stoler, 2016), to consider how different healthcare policies work in the production of bodies and remain as an inheritance for later generations, here it is past family relations and their composition in the present that I want to highlight. Supported by Veena Das (2007, 2015a), I discuss how experiences of pain are embedded in daily life and revived through small details. The question that guides my inquiries is: what textures of time are present in the relations of care?

To work with this question, I raise a specific situation that took place in 2017, when Leonor had been taking care of her mother on her own for four years. The overlapping of the mother-daughter relationship, elderly-caregiver was combined with domestic work and informal paid work, which accumulated and produced attrition on Leonor's body and mind. With the passage of years, the progression of Alzheimer's disease led Dona Carmen to develop insomnia and hallucinations. In 2017, the insomnia and hallucinations had become routine in Leonor's life. However, and as Das (2015a) affirmed, not everything is absorbed in daily life, and it is precisely the encounter of tiredness, insomnia, hallucinations, and memories of pain that I examine in this part of the work. In a desperate moment, Leonor called me for help. Therefore, the history that I describe below was narrated at a distance, on a phone call.

Dona Carmen had been awake for two days and two nights with hallucinations and no sleep. With her mother in this condition, Leonor also did not sleep. Leonor classified the nights that both stayed awake as *nights of terror.* On this night, after struggling, Dona Carmen forced her head between the bars that strategically circled the bed so that she would not fall – she was stuck at the neck. Leonor photographed her mother in this situation and sent me a photo on *WhatsApp*. Dona Carmen shouted insistently that she was stuck, that it hurt and that she would die. Leonor tried to come close to her mother to remove her head from between the bars but, with hallucinations and without recognizing her daughter, Dona Carmen shouted for help, called for the police, and said that Leonor wanted to kill her, stab her, suffocate her. When Leonor came close to her, Dona Carmen shouted even more, she bit and hit Leonor as she writhed in the bed, hurting herself even more. According to Leonor, her mother was *making trouble all night long* and no one slept. She was only able to come close to her mother when she calmed down and asked to eat.

Leonor could not leave the house with her mother stuck between the bars. So, for hours Leonor repeatedly asked Dona Carmen to calm down, said that she had to go out to buy food, that

[15] I refer to the 5th Chapter of my doctoral thesis (Pierobon, 2018), entitled: "Instituições de Saúde: precariedade e conflitos cotidianos". [Healthcare Institutions: precarity and daily conflicts]. In it, I described when Dona Carmen was admitted to hospitals and the relations of care between her and her daughter Leonor.

there was no more food in the house for Dona Carmen who, old and without teeth, needed *healthy and blended* foods. Leonor insisted: *mother, I have teeth, I can eat anything, you can't. Help me so I can take care of you.* Dona Carmen responded shouting: *go to the market, go to the market,* but she refused to let her daughter come close to remove her head from the grates. That is when Leonor called me. She placed the phone close to Dona Carmen so that I could hear her cries. In her understanding, her mother was *wasting away and taking her with her.*

During the hallucination, Dona Carmen began to call for her older daughter, Laura. Dona Carmen shouted that she did not want the *fat one* taking care of her and wanted Laura. *It was Laura, Laura, Laura, the whole time*. The more her mother called for Laura, the more Leonor thought it *complicated* and the more *irritated* she became. Tired, irritated and without sleeping, Leonor said *crazy things* to her mother: *you want Laura, your daughter who slept with your husband?* When she was an adolescent, Laura was abused by their father for years. In Leonor's interpretation, *first it was abuse, then she began to like the perversions*. Laura came to have a son through her relationship with the father. The son lived with various women in the family, including Leonor. The boy was killed at the age of 15 when getting out of a bus. By phone, Leonor told me that in the period when the father had sexual relations with Laura, he threatened Leonor saying that she would be next. For this reason, since she was small, Leonor learned to sleep with a knife under her pillow. To complicate the situation even more, Laura had an affair with Leonor's husband when she was pregnant with her first son. Leonor separated from her husband and Laura was with him for a few years until they also separated. When Dona Carmen called insistently for Laura, these memories came to Leonor's mind. She said she knew that her mother was not *guilty* of getting her head stuck and for calling for Laura, that she was hallucinating, but these memories, were *very strong* and at times she said *crazy things*.

Uterus

> I also remember how, when we were little, the women would take us with them to the sauna. And we saw that all the women's uteruses (this we could understand even then) were falling out, they were tying them up with rags. I saw this. They were falling out because of hard labor.
>
> Svetlana Aleksiévitch,
> Voices from Chernobyl (2006:26)

Upon accompanying Leonor's daily life for 5 years, I watched her age and become ill. As processes, aging and disease should be understood as social and political and over time. In this last portion of the article, I would like to deepen the discussion about the effects that the relationship of care produced on Leonor's body and mind. I emphasize that, although the focus is on the relationship of care of the daughter for the mother, this is not separated from the conditions of poverty and precariousness, of self-responsibility for care, of the memories of pain present in the family histories, of the healthcare policies that act on the vulnerabilities of bodies. To the contrary, to understand the shaping of Leonor's body and mind it is necessary to analyze the various dimensions of life that act in this production. Nevertheless, I conclude the text by presenting the circularity of the production of the vulnerable body among low income women, or in other words, how the production of vulnerabilities become an inheritance for later generations. If above I presented care considering the ambivalence between strength and vulnerability, what I show now is how this strength can also be devastating.

We return to the year 2017. In addition to the advance of Alzheimer's, hallucinations and insomnia, Leonor had to deal with the effects of a fall that Dona Carmen suffered the year before, when she broke her femur. As a result of the fall, the Alzheimer's and her aging, Dona Carmen had increasing difficulties moving around. Whether at home, or in the hospitals, the effect of this limitation was an increasing burden on the domestic work and care work. Since Dona Carmen could not place her leg on the floor, Leonor began to carry her from bed to chair, from chair to sofa, from sofa to a sanitary chair, and so on. These activities, day after day, were taxing Leonor's already tired body and mind.

Dona Carmen had pneumonia. The infection got worse and Leonor had to hospitalize her. After a few years, Leonor maintained her ethic of responsibility that affirmed: *going to the bathroom is one of the few pleasures my mother has in life.* For this reason, Leonor made a point of taking her mother to the bathroom to move her bowels and urinate, even if she had no help from the hospital nurses, because they understood that Dona Carmen should use geriatric diapers. To take her mother with a bad leg to the bathroom, Leonor carried her from the bed to the sanitary chair, and pushed it to the bathroom, and took her back and placed Dona Carmen in bed. Not only did she take her mother to the bathroom as often as necessary but spent 24 hours per day in the hospital caring for her mother: because there were few nurses, and they did not take care of Dona Carmen the way that Leonor did, because her siblings were absent, because the daughter did not want her mother to feel alone.

At times I would visit Dona Carmen and Leonor in the hospital, other times I would substitute Leonor for a few hours so that she could rest. On the tenth day of this dynamic in the hospital, when Leonor was carrying Donna Carmen from the bed to the sanitary chair, her vaginal muscles tore and her bladder descended through her vaginal canal and emerged from her vagina. The biomedical name for the problem is genital prolapse and involves the weakening of the muscles and ligaments that form the pelvic floor. The medical doctor Dráuzio Varella[16] explains on his website that when the muscles of the pelvic floor become weak, support for the bladder, urethra, uterus, intestine, rectum, and other organs becomes compromised and they can enter the vaginal opening. In Leonor's case, her bladder had *fallen* into the vagina, a disease known as cystocele. Among the consequences of the herniated bladder are urinary incontinence, which is also present in Dona Carmen's body.

After this episode in the hospital, Leonor made an appointment with a gynecologist at the public Family Clinic close to her home. She was diagnosed with genital prolapse and surgery was prescribed. When the doctor explained to Leonor that she would be hospitalized for three days and would need six weeks of rest, she decided to not begin the bureaucratic process for the surgery. The argument Leonor used was that she is the *sole caregiver* for her mother, and *lived on the fourth floor of a building without elevators,* that she *could not spend six weeks without going to the supermarket* and that *she had no one to count on* during the recovery period. The doctor understood Leonor's situation, but recommended that, if she had considerable pain, she would return to the Family Clinic, which Leonor did not do.

To care alone for her mother, Leonor preferred not to undergo the surgery. Day after day the genital prolapse became part of her daily life: every time her bladder entered her vaginal canal, Leonor pushed it inside with her hand, tried to put it in the place she thought correct and spent as much time as possible at rest. In the same year, Leonor was diagnosed with glaucoma, but she did not have the money needed for treatment and for this reason she was slowly losing her site. Leonor also needed physical therapy for her arm due to the tendinitis caused by exhaustive domestic work. In 2018, Leonor suffered a domestic accident in which she hit her head on the floor. She decided not to go to the doctor, fearful of leaving Dona Carmen alone. Today, she has diabetes, like Dona Carmen, she lost some of her teeth, also from periodontitis, but was able to obtain dental protheses under Brazil's public healthcare system.

Dona Carmen's progressive insomnia and hallucinations deeply affected Leonor's mind. Exhausted, at times going four to five days without sleeping, Leonor began to feel a will to die so that she could rest. Like much of the low-income population who live in Rio de Janeiro, her home is located in a territory with constant armed conflict. Amid the frequent gun battles, Leonor began to put herself in danger. At times, instead of protecting herself, Leonor placed her body amid the shootings: she would sit on the sidewalk waiting for the conflict to end. In a moment of desperation and extreme exhaustion, Leonor said to me: *I wanted one of those bullets to find me so that I could rest.* Metaphorical or not, this suicidal thinking lasted for months, and then dissipated. Leonor then sought help and through her networks, which in this case included me, we were able to have Dona

[16] Page consulted: https://drauziovarella.uol.com.br/doencas-e-sintomas/prolapso-genital/ Access: 01 Oct. 2020.

Carmen consult a psychiatrist who prescribed medication to control her insomnia and hallucinations. To be able to sleep again was a relief in Leonor's daily life.

To conclude, I would like to think of the relationship between strength, vulnerability and devastation, but also about the possibilities for remaking life, in the terms used by Veena Das (2007). At this time in Leonor's life we see how the pressure from her mother's life and the exhaustion accumulated over the years led her body to become diseased, and her thoughts saw death as the only escape for her exhaustion. The power to make the life of the other was simultaneously producing a devastation in which Leonor reached a physical and mental limit. Strength, vulnerability and devastation show us the complex web of the relations of care, in which are entangled family relations, the memories of pain and the attritions due to the work of care over the years. Inspired by Clara Han (2015) who analyzed how the experience of assassination infiltrated the daily life of a family in the periphery of Santiago, I think that the relationship of care shows us the delicate task of being responsible for the life of the other and discovering the finite quality of difficult circumstances. Thus, to work with the relationship of care of the elderly is to understand that life and death are intertwined to each other (Han, 2015).

Conclusion

The care for an elderly person in daily life is not a simple task, and it is not a responsibility that comes to a quick end. To the contrary, caring for an elderly person can last for years, and the complexity deepens when the care relationship is also a family relationship. Thus, to think of care in daily life means to understand how the relations overlap of elderly-caregiver, mother-daughter and the work of care, domestic work and paid work. To care for an elderly person is not a static task, which is repeated in the same way every day. With the passage of years, bodies and minds change and each change winds up being incorporated to the routine of daily life. The effects that the caring relations produced on bodies and minds of the elderly/mother and caregiver/daughter over time was what triggered my interest in the analysis, and therefore, what I wanted to describe in this article.

By observing the relations of care in daily life I began to realize the importance of analyzing the marks present in the bodies of the caregiver and the person who receives care, as well as the implications of these marks on the care practices. But upon thinking of these marks, I opted to present the specific histories of blindness due to cataracts and loss of teeth caused by periodontitis in the body of Dona Carmen and also the rise of tendinitis and genital prolapse in the body of Leonor. To present these histories allowed me to see how bodies are produced in relationships. Nevertheless, the relationship that I am proposing to consider is not limited to the relationship between mother and daughter, but includes the duress (Stoler, 2016) of the healthcare policies and institutions existing at the time when these illnesses occurred, as well as their socio-economic conditions and family relations. Thus, the relationship that I presented here is a relationship that is not limited to the domestic sphere but includes the successes and failures that compose the healthcare systems, the internal conflicts, the family relations, and the conditions of precariousness.

A third issue that appears important to highlight is how various illnesses are present in a single body and are important for considering care practices in daily life. For example, in the studies that I read that examine care for elderly people with Alzheimer's disease, there are few that combine Alzheimer's with other illnesses such as diabetes or high blood pressure[17]. However, by accompanying Leonor's daily life when caring for her mother, it was often the other illnesses that had a stronger impact on daily life. For this reason, upon examining the work of care for an elderly person who has various illnesses in a single body, I wanted to present the importance of analyzing the complexity of the bodies to denaturalize the processes of illness and aging.

To conclude, I would like to approximate the concept of duress used by Anne Stoler (2016) with that of daily life of Veena Das (2015b). I understand that by observing daily life in its minute details, we can perceive how this duress takes place in daily life, and exercise concrete pressure on

[17] I highlight the delicate work of Cintia Engel (2020) who analyzes Alzheimer's disease and other dementias in association with different disease processes. Through the concept of "drug interactions", the author presents the amount and complexity of drug management in people with dementia and the routine of family members to manage their daily lives.

muscles and minds, whose effects can literally be visceral. To analyze the duress that influences daily life allows us to work with the inseparability of the public and the private in shaping life. To observe the permanence of processes in daily life, allows us to observe how the past and present are intertwined in different scales. For this reason, an anthropology that focuses on ordinary daily life opens us to the complex temporalities that produce life in the present.

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