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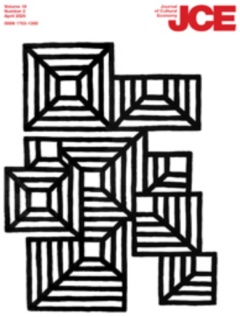

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Responsibilization of care: tensions over health, insurance and the family in Brazil

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ABSTRACT
When people identify a lack of care or formulate requirements for care they also identify responsibilities. Which individuals or what institutions are seen to be responsible for care, including the failure to meet care needs? This question is particularly urgent in Brazil where it is becoming more popular. Brazilian legislation states that homecare patients must receive care from family and professional caregivers whose efforts must be paid for either by a private insurer or by the state. This means that the patient's home becomes a contested meeting ground for the responsibilities of healthcare companies, insurance companies, the state's public healthcare services, and the patient's family. How can that meeting ground be analyzed? We shall argue here that a situational analysis offers a conceptual space to understand the diverse moral contestations that homecare brings about. Moreover, we show how the onus of attempting to resolve various contradictions that emerge when finance and care meet at home tends to fall on the patient's daughters in particular.

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Introduction

When patients receive homecare, their home becomes a symbolic and social configuration that includes kinship, professional caregiving, health insurance companies, and state-funded healthcare services. Care enacts the gendered and kinship moralities that define responsibilities (Amrith and Coe 2022; Borneman 2001; Mattingly 2014). How do cultural, social, and economic values emerge around homecare, and what do these reveal about finance and care in everyday life? Which financial and care responsibilities are contested and by whom and for which reasons?

Over the past 15 years, medically prescribed homecare has become more common in Brazil. Homecare might include anything from consultations and medical treatments to the services of physiotherapists and dieticians; phonologists might be called in, or any of a whole range of medical professionals. Many homecare patients are attended by nurses or assistant nurses, with a number of patients receiving 24-hour care, 7 days a week. Many patients receive hospital beds, medical equipment that monitor the patient's health, or support vital functions. In the cases presented here, those services were provided by private health insurers. Insurance companies have a vital responsibility and so do family members and companies that offer medical services. We found that there are often disagreements about the precise legal and moral nature and extent of these responsibilities, which cause a great deal of tension. Private healthcare markets limit their contribution to healthcare and at the same time influence the responsibilities that are placed upon family members.

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In Brazil, these responsibilities are partly regulated by law: the law requires that at all times, there is a family member with the homecare patient, 24 hours per day, 7 days a week. The family is responsible for a home that meets hygienic and other health standards. That legal requirement places an enormous burden on a patient's family, and as we will show it is daughters in particular who are seen to be responsible. They often organize medical appointments, provide emotional support, create and manage schedules with medical staff, communicate with healthcare providers; and manage the sometimes hard-to-navigate bureaucracies of health insurance companies and public healthcare institutions.

Homecare is becoming more popular since doctors nowadays consider that for certain patients the home is a healthier environment, for example because infection risk is likely to be lower. Family members too, often prefer that a patient remains part of the home, so that they can share in meals or take part in other activities that symbolically define home. In some circumstances, homecare enables a wider emotional and social support structure, plus there might be financial reasons to stimulate it. Medical, legal, and financial experts all told us that homecare is considerably cheaper than hospitalization: in fact it is not uncommon for homecare to cost only a third of hospital care, so that the adoption of homecare has become one of the ways health insurance companies have been trying to mitigate rising medical costs. It might seem that homecare is a win–win situation, but a more detailed analysis shows that homecare gives rise to tensions and inequalities that surface around the definition of responsibilities.

Homecare in Brazil always involves private companies that are contracted by private health insurers or public healthcare administrations. The responsibilities of private companies and of the family have been more clearly defined in 2003 and in 2006. In 2003, the Brazilian state brought into existence the Charter of The Elderly (Estatuto do Idoso, Law 10.741/2003). The charter defines, among others, the responsibilities that children have toward their parents. Children can now be imprisoned for neglecting or abandoning their parents. In 2006, amended legislation defined the insurers' responsibilities more clearly, and this made it more feasible for insurance companies to offer homecare (Franco and Merhy 2008, 5).

Legislation changes how everyday homecare works out in everyday life, but it is also important to acknowledge that there is a discrepancy between the legal responsibilities and everyday understandings of it. We found that it is not uncommon for private health insurance companies to refuse the medical services that doctors prescribe, against the law. In some instances, family members are able to make up for the shortfall, albeit in many such cases at great personal expense. We saw that family members felt unable to meet their care obligations because they lacked the skills, resources and time to do so. Some were having severe emotional struggles with moral responsibilities. How then do legal and moral boundaries and contestation emerge when health insurers, private companies and family members see their responsibilities towards the patient differently? Family members are forced to make do with the limited healthcare provided by insurers, and, as we shall see, that often leads to tension between families and insurers, as well as among individual family members. We use the term 'responsibilization' to refer to that tension; the term is intended to highlight the fact that in practice responsibilities are both temporal and situational, and therefore open to interpretation and contestation.

We examine three homecare situations in great detail. Taken together they reveal the diverse struggles and contestations among family members and insurance companies, but they show also that it is especially daughters who end up having responsibilities imposed upon them. They were the ones most often confronted with the tensions that emerged over care for their elderly parents, and they were most likely to fill the care gaps left by insurance companies or other family members. Homecare in Brazil, stimulated as a win–win situation to curb rising healthcare costs, profoundly changes daughters' social networks, as well as their senses of personhood (see among others Guyer 1995). Today's homecare demands have, we argue, forced daughters to reconsider the gendered and familial discourses that are central to care, personhood, as well as political struggles in Brazil.

The first case, one of distance-caring, concerns Adriana, who was her father's carer, even though he was living more than 700 km (400 miles) away. Adriana's experience foregrounds how social class and generational differences affect responsibilization. The second case concerns Simone who experiences a 'life gap' by caring for her mother, Nair. The third case was of a son and daughter caring for their mother, Maria, and both were struggling with the emotional and social consequences of their obligations. Providing healthcare and dealing with the insurance company confronted them with deep-seated gendered and class-related ideologies. Their individual anxieties reflect gendered family relations, political ideologies, and what is expected of the market.

The three cases are based on fieldwork in Brasília during research visits totaling approximately 9 months from 2017 to 2019. The conversations with Adriana took place in Fabíola's apartment and were complemented by shorter online conversations, via WhatsApp among other media. The conversations with Simone and with Maria's son and daughter took place at the Public Defender's office, the Public Defender being an independent government institution providing legal support, which helped Simone, and Maria's children to initiate legal processes against their insurance companies. We reviewed dozens of other court cases but selected the two presented here as they are particularly revealing of the complex responsibilities around homecare. This study is also informed by approximately 200 interviews with professionals working in the insurance sector, policy makers, health economists, actuaries, medical professionals, and professionals working for agencies providing homecare services, and lawyers; and of course we spoke to family members of patients.

Responsibilization and the kinship/market nexus

Insurance companies enable healthcare but also put bureaucratic obstacles in place that actually hamper healthcare (Dao and Mulligan 2016; Dao and Nichter 2016; Mulligan 2013; Mulligan and Brunson 2022). Insurance premiums pay for healthcare but only so for certain people, or only in certain circumstances, thus limiting the responsibilities of financial companies (Kusimba 2021; Prince 2023; Zeldes 2023). Insurance companies enable solidarity but do this by defining boundaries that inherently limit their responsibilities (Bähre 2020).

Hochschild (2003) argued that capitalism contributes to a growing care-gap in society. She identified a self-perpetuating process where an expanding market frontier creates a 'postindustrial family', which then augments questionable moralities that undermine care practices: 'Increasingly we feel in our moments of detachment and neglect the referred pain of unfettered global capitalism itself' (Hochschild 2003, 3).

Tronto (2015) has argued in a similar direction: The growing 'caring deficit' is the result of the rise of a political ideology that stimulates market thinking. The market, Tronto argues, erodes moralities and relationalities and therefore also erodes care practices that are 'always relational' (Tronto 2015, 4). These relationalities are being undermined by neoliberalism:[1] 'We need to stop trusting that "the market" will somehow magically meet all caring needs' (Tronto 2015, 37).

Nguyen, Zavoretti, and Tronto (2017) also hold that neoliberal ideologies are responsible for care problems, but point to a different dynamic, arguing that a contradictory process is unfolding by which

> the moral logics of care drive people to engage in actions that are both productive for building communal and ethical lives and reproducing the very ideal of the self-interested individual that eventually undermine the solidary linkages that gels society together. (Nguyen, Zavoretti, and Tronto 2017, 210)

Holding capitalism and markets responsible for the lack of care appears to be a reworking of Simmel (1900). Simmel argued that money and markets make it possible to integrate people into larger abstract institutional arrangements. Money and markets enable individual freedom only by replacing personal ties with impersonal relationships. That view on money and markets has been questioned at least since Bloch and Parry (1989) but seems to be implicit in explanations that equate care with relationality and define care as the opposite of markets, money, and capitalism.

There are more examples of this Simmelian argument in the study of neoliberalism. Liebenberg, Ungar, and Ikeda (2015) argued that the lack of care for children is the result of a process of responsibilization by which obligations are transferred from the state to the market, a transfer, they argue, which is itself the result of neoliberal discourses. Nguyen (2021) argued that neoliberal discourses give rise to a new familialism that insists that the family, and especially women, ought to be responsible for providing care. Neoliberalism, according to Nguyen, gives rise to a new prudentialism that holds the individual responsible for managing risk and that loads the risks of global finance onto individuals (Nguyen 2021, 336). A study of the UK National Health Service holds that policies intended to promote healthier life choices adopt a neoliberal ideology: for example through 'nudging'. That, the authors argue, makes patients unwittingly responsible for their own health, thus undermining collective responsibility (Brown, Maslen, and Savulescu 2019).

Golomski (2018) in turn has pointed to the specific configuration of South Africa's private health insurance and public healthcare to argue that both have increased the extent of paternalism and are reproducing old racial and class divisions in South Africa. Prince (2023) analyzed the evisceration of public health care in Kenya, where increasing costs, paired with limited health insurance, are leaving the middle classes ever more vulnerable to catastrophic medical debt. Prince has observed a 'destructive form of hope' that is 'essential to the workings of late capitalism' that, in the end, places the burden of costly care onto families (Prince 2023, 605). Mulligan and Brunson (2022) argue that the Affordable Care Act in the United States provides healthcare, but at the same time contributes to growing political resentment that undermines care. Studies by Dao (2020) and Fletcher (2017) complicate the nexus of care and capitalism even further, showing that in Vietnam (Dao 2020) and the United States (Fletcher 2017) *not* taking out health insurance can be seen as the responsible thing to do. They show that people can have compelling reasons to prioritize other financial, social, and moral obligations, and that too may be seen as a sign of acting responsibly.

Such varied approaches to the nexus of care and capitalism, each with a specific view of the responsibility of markets, demand an urgent understanding of how people involved in homecare experience and identify responsibilities. Homecare configurations are a salient case to identify how the contested responsibilities of the insurance sector, the state, private healthcare companies, 'capitalism' at large, the family and other 'stakeholders' are being reconfigured. Reece has made the important point that 'care is routinely subject to and productive of crisis, if in different ways at different times' (Reece 2022, 24). Homecare often poses this sense of crisis and raises the question: how do people who are involved in homecare identify this crisis of care and who or what is held responsible?

Certainly, antagonism between care and capitalism is a possible configuration, but it is essential to consider also that there other configurations of capitalism and care (Bähre 2020; Dao 2020; Hart 2015; Kusimba 2021; Maurer 2008; Zelizer 2005). In this study, we have taken an empirical approach by studying concrete situations (Kapferer 2015; Niehaus 2013; Sahlins 2004). We took each of our selected events as examples of a 'critical site of emergence, manifesting the singularity of a particular multiplicity within tensional space and opening toward new horizons of potential' (Kapferer 2015, 16). Homecare not only reflects or reveals moralities but is considered a starting place of emergent moralities as people are confronted with dilemmas. An event is thus 'a wellspring of emergence that is not merely a reflection (or illustration) of the world around it' (Kapferer 2015, 16). Our detailed analysis of specific homecare cases revealed how people are confronted with tensions over care, finance and the family, and we argue that our methodological approach enabled us to uncover the various and contradictory ways in which people perceive care and finance.

Biehl's ([1985] 2013, 2012) ethnographic research on care in Brazil points to how neoliberalism and privatization undermine the care and protection that the Brazilian state is supposed to offer. However, he argues also that it should be recognized that markets do enable care and security, and he therefore calls for a more nuanced approach to moral personhood. Biehl argues that caregiving, in whatever shape or form, 'is intimately bound to the possibility of disregard and evil' (Biehl

2012, 248; see also Bähre 2020). His plea resonates with Reynolds Whyte (2009) who argued that we need ethnographic approaches that place people's lived worlds at the center of any analysis of care. We can then better understand how struggles over care emerge and if those struggles are the result of global political economic forces or have other, perhaps complementary causes (see also Green and Lawson 2011).

By financing and organizing homecare, private insurance companies shift legal and moral parameters and redefine the boundaries of the responsibilities of family and the financial sector. But how exactly do professionals, family members, and others who are involved in care perceive the demands placed on them? What kinds of conflict do they identify and what explanations are given for their emergence? Such questions, we will show, are best explored by the study of actual events that have confronted people with immediate and pressing concerns, sometimes related to the life or death of a family member. When homecare emerges as a new configuration of kinship and of the market, how do people identify crisis and whom or what do they hold responsible for causing or solving that situation?

A specific history

Since 1989, Brazil has had a Unified Health System or SUS (*Sistema Único de Saúde*) consisting of a network of public hospitals and other medical institutions that offer a wide range of basic and specialized healthcare treatment, including home care (Castro et al. 2019; Paim et al. 2011). The SUS contributes greatly to healthcare, but at the same time falls short of guaranteeing access to public health for all. According to Lavinas (2017), this is among others due to the financialization of the welfare state. During his first presidency, President Lula (2003–2011) made a great effort to diminish Brazil's economic inequalities by starting the Zero Hunger strategy. His administration implemented extensive and very successful cash-grant arrangements, of which the *bolsa família* is the most renowned. It improved the living conditions, wellbeing and dignity of approximately 50 million Brazilians (Silva 2022). Lavinas (2017) shows that while such cash-transfer programs were successful in reducing poverty, they had the unintended consequence the individualization and financialization of welfare. She shows how collective rights, most notably the right to healthcare, inadvertently were replaced by individual cash entitlements that were so crucial to the Zero Hunger strategy (Lavinas 2017).

Brazil's collective health system was also affected by the economic crisis that hit Brazil after the financial crisis of 2007. The Temer administration (2016–2018) passed austerity laws that severely restricted the healthcare budget for decades to come (Doniec, Dall'Alba, and King 2016). Although the SUS continues to offer vital healthcare services to millions of Brazilians, the increased strain on public healthcare is palpable. During our interviews, family members of patients were sometimes literally in tears when they told us that their parent, child, or partner did not receive the healthcare that was needed. Doctors and other medical professionals shared with us the tremendous pressure that they experienced, and spoke of long working hours and the frustration of being unable to provide the care their patients needed. Many of them had already left public healthcare to take up exclusively private practice, or said that they wished to do so.

Private health insurance has existed in Brazil since the beginning of the twentieth century, preceding public health provision therefore by well over half a century (Carvalho and Cecílio 2007; Paim et al. 2011). Today, Brazil is the second biggest health insurance market in the world, surpassed only by the United States (Greca and Fitzgerald 2022). Approximately a quarter of the entire Brazilian population is covered by private health insurance, with the highest percentages in urban areas like Brasília, where more than 30% of the population can afford it, and where this study was carried out (ANS 2021, 14). Many Brazilians, not just the elite, pay for private health insurance and have access to private doctors, clinics, hospitals, and other medical services such as home care. The decision to opt for private health insurance seems to have increased since the COVID-19 pandemic, perhaps because many Brazilians could then see for themselves how the public system was overburdened (Salles and Corsini 2021).

A challenge for the provision of public and private healthcare is that Brazil is one of the quickest-ageing countries in the world. Improved living standards, successful poverty alleviation, urbanization, and provision of basic healthcare as well as the SUS have contributed to longevity. The older population (60+) has increased by 6.3 times from 1950 to 2005 and is expected to increase by almost 300% to 2050. It is expected that by 2027 there will be as many people over 60 as there are people up to 14 years old, and that there will be more than twice as many by 2050. In the years to come, ever more Brazilians will be over 80 years old (Gragnolati, Jorgensen, and Fruttero 2011, 60–61) and longevity puts an increasing strain on financial resources, affecting intergenerational solidarity and the gendered, racial and economic inequalities of care relationships.

Care relationships also change due to urbanization. In 1960 for example, fewer than half of Brazilians lived in urban areas, while today nearly 90% do so (World Bank 2022). During our fieldwork, we noted that the family networks that can be mobilized for taking care of elderly have become smaller and more dispersed. Machado (2001) pointed out that although urbanization led to individualization, it did not lead to the demise of a strong moral discourse regarding the family. To understand the Brazilian reconfiguration of individuality and family morality, Machado points out that people without family evoke pity, even in an individualized society. They are seen as abandoned, as the victims of utterly cruel and low class behavior by people who lack decent moral standards. Family, Machado argues, continues to be important because it is first and foremost defined by reciprocal obligations, more so than by sanguinity or consanguinity. The reciprocal obligations of care continue to reflect a patriarchal ideology, also in Brazil's rapidly urbanizing and individualizing context (Machado 2001).

Other social configurations that facilitate care, such as those between employers and domestic workers or nannies, have also changed. Over the past 20 years, care work has become more formalized with clearer labor rights, yet the care that domestic workers and nannies do is still couched in a familial discourse of gifts and intimacy that legitimizes unequal relationships (Brites 2007; Brites and Fonseca 2014; Hirata and Guimarães 2012). Such familial care discourses continue to legitimize economic, gendered, and racial inequalities. Care and finance were never separate domains but homecare that is financed by insurance companies does lead to new struggles over these responsibilities. How do the two major changes – the financialization of healthcare and increased individualization alongside the reworking of moral discourses about the family – play out in the responsibilization of care?

Caring at a distance

Adriana grew up in a midsized town in the state of Minas Gerais, about 6 hours by car from Brasília. Adriana's father Flávio was diagnosed with colon cancer in 2016 and Adriana's main task became to make sure that the insurance company fulfilled its obligations to her father. As Adriana talked about her parents she recognized that the world they lived in was different from hers. Insisting that she did not look down on them, she nevertheless explained to us how relevant it was that she had a university education and was qualified as a dentist, while her parents had very little education. Her parents accepted what doctors or others in positions of authority told them; they would never question them about Flávio's diagnosis nor about his treatment, nor in fact any other decisions that might affect his health. They had, she said, learned to except whatever situation they found themselves in. Adriana's two siblings, who lived geographically closer to her parents, were the same, lacking also the skills and even the disposition, to question authority or to deal with healthcare systems. They certainly did not have the confidence to take on the world of insurance with its dauntingly complex bureaucracy. As Adriana herself put it:

> My sister helps by paying the insurance premium, my brother does not have patience for this. My mother is too old and she just accepts things. The poor – but also the middle class! – accept a lot, especially when they belong to my parents' generation. They think of themselves as humble people and down to earth and they look up to people in a hospital or office. My mother is middle class: I mean *middle*, *middle*, *middle* of the *middle* class. With little education and not much money. She takes the hospital treatment as a gift, even though she knows it is not for free.

In contrast to her parents, Adriana took it upon herself to demand that her father receive what he was entitled to. Her story showed that she made sure that her parents moved away from the hierarchies that are inherent in the gift, the view that is so central to her parents' worldview, and had encouraged then to demand instead the rights that came with purchasing a health insurance policy. As a trained dentist, Adriana is a well-educated professional who knows her way around the healthcare system, could understand bureaucratic complexity, and was used to seeing herself as a consumer possessing rights that were engrained in market obligations.

There were a number of problems with the insurer. Flávio's treatment had begun with chemotherapy, and the closest hospital both able to offer that treatment and covered by the insurer was 60 km away. Flávio went there twice a week and for four months all went well; but then it was decided that the treatment must take place at Flávio's home. At first, nobody knew why the treatment changed and Adriana's parents did not ask the doctors anything and accepted the change. Moreover, they considered the change a good thing, as Flávio would not need to travel. At home however, Flávio's health began to deteriorate and his Adriana wondered why that was.

Eventually – and only after numerous phone calls with her parents – Adriana was able to understand how the situation had developed. She realized that the decision for home treatment had been made by the insurance company, which had hired its expert and followed his advice to change the treatment from hospital to home. At home, Flávio could be given different medication requiring less intense medical supervision. Adriana found out that the insurer had never consulted Flávio's doctor, only the expert they had hired. She was convinced that the insurer's main concern was saving money at the expense of her father's health and ultimately his life. She knew from her own experience working as a dentist that many such experts were far from independent, with many of them put under pressure by insurance companies to give whatever advice that suited the company's interests. She also managed to find out that Flávio's doctor had been against the change, but that he was only too aware that he could give only the treatment that the insurer had authorized.

'I called the company 300 times!' Adriana said. She first thought it best to try to maintain friendly terms with the insurer and to subtly highlight her own medical background. She used medical terms, hoping that this would make a difference, but found that it did not help, and that the bureaucracy was 'wrapping her up': she used the term *enrolação*, a popular reference to how bureaucracy disempowers the individual. Adriana noticed that the *enrolação* stopped only when she became more assertive; she decided she would stay friendly and professional but when contacting the insurer also made it clear that she was 'going to make a row' as she put it herself.

She asked her father's doctor to write a medical report which she could use to put the insurer under pressure. He wrote that Flávio's home treatment was less effective such that it threatened his life. It was risking infections that could not be dealt with at home and had led also to diarrhea and vomiting. The doctor wrote that Adriana would sue the insurer on behalf of her father and that he was convinced she would win. Adriana appreciated the doctor's helpfulness but pointed out that he only became helpful after she herself had pressed him for assistance.

Another way to put pressure on the insurance company was by posting a complaint on 'Reclame Aqui'. 'Complain Here' is a website that publishes complaints from consumers, and companies too may use the site to contact complainants. The site uses consumer evaluations also to rank companies, which of course affects their reputations. Adriana posted her complaint one Friday and the insurer contacted her the next working day, informing her that they were keen to resolve the problem. She talked to the insurer and to impress them she lied that she had already hired legal representation to take them to court. Polite but assertive, she said that she was also preparing an official complaint to the Agência Nacional de Saúde Suplementar (ANS), a government organization that since 2000 has been responsible for regulating Brazil's private health sector. The ANS is empowered to impose substantial fines on health insurers that do not comply with their regulations.

When reflecting on her strategy, Adriana smilingly said: 'I always stayed polite, but it was clear that I was ready for them! … They know they are not dealing with a lay person'. And the strategy worked: the insurance company revoked its earlier decision and agreed that Flávio should again receive hospital treatment. Flávio's health indeed improved considerably and the doctor eventually told Flávio that he was cured. However, the next year the cancer returned, and although this time the insurance company immediately authorized all his doctor's prescribed treatment, this time Flávio's life could not be saved and he died after only a few months. At times, Adriana admitted, she could not help but think that he might still be alive if the insurer had not forced home treatment.

Adriana's idea of care was different from that of her parents and siblings, for unlike them Adriana saw healthcare as a right. She refused to accept at face value the authority of professionals whether medical or from the insurance world, preferring instead to fight for her father's right as a consumer. 'Hundreds of calls'; prevailing upon her father's doctor to write a medical report; posting a review on an influential consumer website; politely threatening to complain to the ANS and if need be take legal action; all amounted to Adriana's way of caring for her father. Even from a distance therefore, she had been able to mobilize her professionalism in a way her parents and siblings could not have. Although health insurance enabled new forms of care by relying on patients' homes and families, it created simultaneously a demand for a new form of care, which would now include skills and the ability to manage an insurance company's bureaucracy. As Adriana's experience shows, that is a complex task requiring a particular understanding of the market.

From 'care gap' to 'life gap'

We met Simone, who takes care of her mother Nair, during an appointment with the Public Defender. Taking care of her mother was a heavy burden on Simone and during our conversation she mentioned that she was sacrificing her life to take care of her mother. Simone expressed her anxieties and worries reluctantly, telling us repeatedly that she loved her mother, and that we must realize that she cared about her, felt responsible for her, and that she was perfectly willing to care for her. But, at the same time, Simone admitted: 'My life has stopped because I have to take care of my mother'.

After her father's death a few years previously Simone's mother Nair's care needs became more intensive. She was eventually hospitalized with pneumonia and was diagnosed with dementia too, for which medication was prescribed which helped a little. A recurring problem, however, was that Nair sometimes refused to eat as she suspected that people, including her daughter, were trying to poison her. Simone, with her degree in psychology, understood that this was a symptom of her mother's dementia, but found the situation no less difficult to deal with. To secure Nair's survival, she was given a catheter and whenever she refused to eat, they would feed her via a drip.

Over the previous year, Nair had been in and out of hospital, sometimes admitted to intensive care, sometimes to a regular medical ward; she would then be discharged and receive homecare, only to be re-admitted to hospital when her health deteriorated again. Simone visited her mother regularly, and talked with nurses and doctors about her health, and all the medical checks and records. As Simone herself acknowledged, she did so as much as anything to convince herself that Nair was not being abandoned by her family, the hospital, or the insurance company. Whenever Nair was discharged, she received homecare for her pneumonia and was intubated whenever she refused to eat.

Caring for her mother meant also that Simone's home arrangements had changed. Simone explained that she was divorced and together with her daughter Christina had moved into her parents' home, which at first had seemed the most convenient thing. However, Christina soon began to miss her friends who all lived near their old house, about 20 km away and where her father still lived. Christina had been forced to attend a different school and missed her old school also. Another problem was that Christina could not get along with her grandmother; Simone for her part felt that her daughter had too little patience with Nair and was refusing to accept that Nair's erratic behavior was caused by her dementia. At the same time, Simone also understood that her teenaged daughter had other concerns that overrode her consideration of her grandmother's health. Eventually therefore, they had decided that Christina should live with her father and visit her mother and grandmother only every so often. The new arrangement had eased the tensions between grandmother and granddaughter but also meant that Simone's relationship with her daughter had become more distant. Reflecting on our conversation, Simone added: 'All this [our conversation] makes me think about how much our lives, including that of grandmother, granddaughter and myself, are affected by the health of my mother and the care that I have to give her'.

Simone has three brothers who pay for a domestic worker to relieve Simone of some of her tasks. Her brothers were in work and Simone understood that this was the best way for them to help, although she lamented that the domestic worker was not up to the tasks they had envisioned for her. Moreover, Nair often needed help at times when the domestic worker was not there, and even when she was present, the domestic lacked the proper skills. Simone had to accept that she must do most of the personal care herself, while the domestic worker did everyday household tasks.

The pressure on Simone was then further increased when the insurance broker contacted her to explain that the company would need to 'migrate' the policy because, they said, the company was about to close it. The company's representative assured her that a new policy would be set up with a new company that would be as good as the old one. The whole matter was a simple administrative task for which Simone need only give her approval, he said. However, it didn't take long for the broker to inform Simone that the new insurance company would not accept Nair as a client, leaving Nair without health insurance.

The Public Defender then prepared a petition and took the insurance company to court, where the judge ruled that the insurance company had committed fraud. The insurer had made a false statement about Nair in an attempt to avoid regulations of the Agência Nacional de Saúde Suplementar (ANS). To put it simply, the insurer had pretended that Nair's policy was with a company, which it was not. The judge ordered the insurer to reinstate the contract and, given Nair's advanced age, further ruled that cancelling the policy had threatened Nair's health and life. The company and broker were ordered to pay Nair R$5000 in punitive moral damages, in compensation for the violation of her dignity.[2]

What, then, do the events described by Simone reveal about changing responsibilities? For Nair, there seemed to be no 'care gap' or 'care deficit'. After all, from her point of view as relayed by her daughter, she was receiving the care she needed. When we focus our attention on Simone, we see a more problematic situation. Simone had experienced a major interruption of her life and during our conversation she realized that she was sacrificing herself for her mother. Sacrificing one's life is undoubtedly the greatest gift of all; but we can see how the tension that Machado (2001) called to our attention had become a problem for Simone. On the one hand, Simone was experiencing the consequences of a strong familial discourse; she herself was careful to insist to us that she would never abandon her mother. At the same time, Simone was not part of an extensive family network with whom she could share the job of caring for her mother. In fact, Brazilian law on homecare and caring for elderly had isolated her from her family. Even the trials and tribulations with the insurer and the court case had fallen on Simone's shoulders.

Biehl ([1985] 2013) and Niehaus (2007) revealed how socially, patients can become the equivalent of dead. Biehl ([1985] 2013) described how a patient came to be abandoned by the Brazilian state and by her family, to end up so marginalized that she became a non-citizen, almost a non-person. Niehaus (2007) explained how in South Africa the stigma of HIV-AIDS and its popular association with zombies and lepers, leads to silence, and exclusion from society so that people experience 'death before dying', as the title of his article puts it.

Simone was not a patient but a caretaker, but her account of her life reminds one of 'social death', as a form of social absence – or at least retraction. Simone had experienced first-hand how measures to reduce the cost of healthcare, national legislation intended to guarantee adequate homecare, and a process of individualization coupled with the continuance of a patriarchal ideology based on gendered mutual obligations, had led to the 'social death' of the caretaker. Simone's social life and aspirations had been put 'on hold', not those of her mother, the patient. Simone's 'social death' – and that of others like her – was one consequence of her submitting to gendered care obligations, paradoxically of her *not* abandoning her family.

Confronting ideologies

We met Marcelo and Hermínia at the Public Defender's office where we found them wishing to sue their insurance company on behalf of their 82-year-old mother Maria. Maria had been in the hospital with pneumonia for 2 months, and the insurer had authorized all her prescribed treatments. The problems started after Maria had been discharged, and the doctor had prescribed home healthcare. Maria had a gastrostomy and had to be tube-fed. She had difficulty breathing because of fluid build-up in her lungs, so she needed oxygen, and medication that was administered via a nebulizer. A doctor visited Maria's home for routine fortnightly check-ups and she saw a physiotherapist three times a week, a phono audiologist weekly, and a nutritionist monthly. The doctor prescribed that a nurse or assistant nurse would take care of Maria 24 hours per day, 7 days a week, but the insurer only paid for 12 hours per day.

To contest the insurer's decision to provide only 12 hours daily homecare, Marcelo reminded the insurer that they were legally bound to comply with the doctor's prescription. The insurer then explained to Marcelo that his mother did not score highly enough on their homecare index. Marcelo, clearly upset, said: 'Can you believe it? An "index"! I get all worked up again just telling you about this.' He found it dehumanizing and unfair that their mother's life and health could be quantified in such a way; he even began to sketch some calculations of his own for us.[3] He reckoned that Maria had paid health insurance premiums for 10 years, and that they had always been trustworthy and loyal clients:

> I calculated how much we have spent on my mother's insurance and over the past ten years: R$168,000 Reais [at the time approximately US$ 9,000]. Maybe that's why the insurer at least agreed to pay part of the homecare [instead of completely denying homecare]: But they've profited a lot from her already.

Marcelo is convinced that the insurer had made a similar calculation and realized that they were losing money on Maria. He was certain that, and not the index, was why they had refused to provide more than 12 hours of homecare. Marcelo and Hermínia both felt that the personnel they spoke with suggested that they, the children, secretly were using the insurance company to abandon their mother. That suggestion had upset them enormously.

A pressing and acute health problem for Maria was that she was suffering from an infection close to her tailbone, caused by a lesion. Keeping the wound clean was especially urgent as Maria was unable to control her bowels. The nurse had showed Marcelo and Hermínia how to clean and dress the wound but Marcelo in particular felt highly uncomfortable doing this. He explained that not only did he lack the medical expertise but, more importantly, he felt too emotionally affected by his closeness to her to be able to do this:

> I don't have enough distance from her and when I take care of her I'm afraid I'll hurt her, or I'll see that she's in pain and then stop what I'm doing to stop the pain. But … she needs the medical attention.

Tronto's (2015) distinction between forms of care helps us understand Marcelo's predicament. Caring *about* his mother made it difficult, maybe even impossible, for Marcelo to care *for* his mother, at least in that intimate physical way. There were for Marcelo also related notions of masculinity. As a man he might be expected to provide financial or practical aid, such as running errands, but would not be called upon to deal directly with a patient's bodily needs. We found that people who considered themselves part of a broad and ideologically charged 'middle class' were more likely to leave physical care to hired personnel, such as domestic workers, nannies, or relatively even more inexpensive female caretakers (see Brites 2007; Hirata and Guimarães 2012). Marcelo felt distress not only because his mother's health was in the balance but also because the gendered, racial and class-related ideologies that he himself identified with were being fundamentally challenged by the insurer's decision to provide only 12 hours of homecare.

Marcelo also insisted to us that he did not want to abandon his mother. He explained in detail that Maria received thirteen types of medication every day and all had to be administered at exactly the right time; he emphasized to us that Maria's health would be severely compromised if they should make any mistake:

> If I give the wrong medication I could kill my mother. This is a huge stress for the whole family. If she dies while I'm taking care of her, I'll think I failed and I'll never forgive myself. I'll have to live with that for the rest of my life and will never be sure if she would have lived if I'd done something different.

One day indeed, Maria nearly did die at Marcelo's hands. Marcelo had to remove the fluid that had built up in his mother's lungs, otherwise she was going to suffocate. He had found it difficult to follow the nurse's instructions although eventually he succeeded. The nurse arrived in time to take over, but still Marcelo remained convinced that Maria had only narrowly escaped death at his, Marcelo's, own hands. Marcelo again shared his agony with us: 'I'm not prepared for this. If I do something wrong, I'll never forgive myself. I don't want this responsibility, and I can't bear it.' His sister Hermínia added: 'When I do the aspiration, I almost die from fear of hurting my mother. And the companies, they only look at it from the financial side. But there is a human side.' Hermínia had realized that most insurance companies do not even give 12 hours homecare, but nonetheless she did want to sue the insurance company.

During our conversation, the Public Defender had prepared a petition that included medical and contractual details, and a few weeks later they had received the preliminary ruling. In Maria's case too, the judge had ordered the insurance company to follow the doctor's prescription and provide a nurse or nursing assistant 24 hours a day, 7 days a week. The final ruling followed 6 months later and upheld the preliminary ruling.

A closer look at the court proceedings reveals that the insurance company had not originally authorized 24/7 homecare because that service had not been included in the insurance contract. The insurer furthermore argued that the ANS does not in fact require insurers to provide homecare. The judge agreed, but argued that a client may expect to receive the best treatment and that it is the doctor who decides what that best treatment is. Moreover, the constitutional right to health overrides contract and ANS regulations. The judge argued that in the light of that constitutional right it was abusive to have presented the client with a contract that excluded homecare services (see also Bähre 2023). The insurance company appealed the following day, arguing that 24-hour home care was not medically necessary but was being sought purely for the family's convenience. Just as they had to Marcelo and Hermínia in person, the insurers insinuated to the judge that Maria's children were attempting to shift their moral responsibility for care onto the insurer. During the appeal process, which took 6 months, the insurer had been required to provide 24/7 homecare, and again, the judge ruled in favor of Maria:

> It is evident that the in-patient service domicile [homecare] is not a matter of mere convenience for the insured and her family members, but of real need for a dignified maintenance of her life and health.

The insurer was obliged therefore to continue providing 24/7 homecare and was ordered to pay Maria R$10,000 moral damages for violating her dignity.

Their mother's illness and decline confronted Marcelo and Hermínia with deep-seated and prevailing ideologies about gender, class and family, as well as the responsibilities of market and family. The insurer accused Marcelo and Hermínia of using insurance to abandon their mother, and trying to evade their obligations to her. Moreover, Marcelo in particular was angry that the insurer had measured his mother's health against an index that he took as a poor attempt at veiling their financial calculations. The struggles over how to take care of Maria thus involved complex references to the legal and ideological responsibilities of the family on the one hand, and financial companies on the other, while the court cases revolved around family morality. The final verdicts revealed that the constitutional right to healthcare prevailed over insurance contracts and even ANS regulations; that the family was not trying to use the insurer to dodge responsibilities; and that the insurer must financially compensate Maria, their client, for affronting her dignity.

Responsibilities: rethinking the focus

It is not always capitalism, neoliberalism, or other invocations of the market that are responsible for the lack of care that patients receive. A detailed analysis of how health insurance affects responsibilities shows that the care/finance nexus can play out in very different ways. Finance can hamper access to healthcare but also support carers and relieve them from unequal care relations (Brites and Fonseca 2014; Buch 2015; Pedroso de Lima 2016). A too narrow perspective on access to healthcare as governed by finance risks overlooking the complex and contradictory dynamics of finance and family. It also risks undertheorizing other changes that affect access to care as well as the changing responsibilities.

By focusing on responsibilization we have broadened the perspective on healthcare which offers nuance to the relationship between finance and care. Following Kapferer (2015), we analyzed actual events, or sequences of related events, as an emergence of moralities and thus do not assume that a certain morality regarding capitalism and care is already there. People's commentaries on events, a detailed analysis of court cases and contractual obligations, study of how national legislation and constitutional rights are mobilized in particular ways; all play a role in how particular moralities unfold when people and institutions are confronted with their responsibilities. We have described here differences in feelings – of indignity, of anger; the fear of abandonment, social death – as well as anxieties about the intersectional inequalities on which both care and finance are premised. In abstract policy terms and models, homecare is presented as a solution to increasing healthcare costs. Claims are made that it will reduce medical risks supposedly inherent in hospitalization, save money, and meet the healthcare needs related to a steadily ageing population. For those Brazilians who can afford private health insurance, homecare has become a meeting ground, but even more so a site of organization and moral contestation over family and finance.

These struggles over responsibilities show how gendered, patriarchal and class-related ideologies are being reworked when insurance becomes part of care arrangements. Some people cast care in terms of reciprocal obligations, while others defined it as a right available to consumers via the market. Others experienced the insurance sector as dehumanizing, especially when confronted with their calculations. The methodological approach adopted here, with a focus on actual events, places such everyday struggles and contradictions right at the center, and therefore offers a nuanced conceptual space. This is not to deny that powerful global economic discourses change care arrangements in Brazil just as in the rest of the world. In Brazil too, there are immensely wide care gaps and inequalities, and the cases described here reveal that in certain circumstances, and at certain moments, health insurance is hostile to care and even to human dignity. Yet at certain moments, the services that insurance companies provide did become part of relational care practices (see also Weber 2006) and by providing homecare, insurance companies facilitated care *and* relatedness. They facilitated care by financing and organizing healthcare and enabled relatedness by providing professional care workers. But these shifts are intimately related to the responsibilities of family members, as prescribed by law, and here we see that in this emerging configuration daughters become especially responsible for care.

The tensions over responsibilities were only partly located somewhere between finance and care. They were also related to ageing and individualization as well as other demographic changes; they were related to legal changes that more precisely defined the responsibilities of healthcare companies, insurers and family members; they were related to a process of emancipation that made the racial, economic, and gendered inequalities on which care is premised less palpable, at least to some extent. Insurance companies sometimes helped to organize healthcare and sometimes relied on family members to develop new forms of care, including handling its complex bureaucracy. Insurance was sometimes responsible also for creating situations in which the lives of carers, but not necessarily of patients, became seriously disrupted, all to combat rising medical costs. Health inequality was therefore reflected more clearly in the lives of carers than in those of patients, which draws our attention to the relatedness of the care made possible by financial instruments.

Daughters especially found themselves alone at the crossroads of contested and contradictory responsibilities. They, more than other family members, experienced how the responsibility for creating a caring home could be both mutual and contested. Encounters with insurance companies revealed how daughters were challenged to develop their notions of personal morality. Actual events in their lives confronted daughters with notions of what it is to be a consumer in a market while having to live as gendered beings with gendered responsibilities. For a number of such women, socio-economic mobility had allowed them to navigate around the pitfalls of bureaucracy. Others, under pressure from healthcare professionals, felt enormous anxiety when faced with the need themselves to exercise essential and sometimes life-saving skills they knew or at least strongly believed they lacked; and that is saying nothing of the social seclusion of caregivers, even if not of patients.

To some extent, insurance companies have replaced the care that was once based on unequal care arrangements that were cast in terms of reciprocity. The racial, class and gendered hierarchies of the past – which couched care within a discourse of unequal reciprocal obligations – have lost some of their ideological terrain. To some extent at least, private health insurance is filling a care gap that has in fact been created in the wake of a process of emancipation that challenged those very inequalities on which care was premised. At the same time, ideologies concerning abandonment resonated with moral distinctions where the poor were defined as immoral because they could be seen as abandoning their families and stigmatized for it (Machado 2001; see also Biehl [1985] 2013). Even in a court of law, at least one insurance company drew on that same discourse of abandonment to argue that they should not be expected to replace family obligations. That company was drawing on a discourse that is in fact pivotal to Brazil's divided political landscape where right-wing and certain Christian ideologies emphasize that caring for family is a defining characteristic of the middle-class identity as being morally correct individuals who are also commercially aware consumers. For some people, finance and the market were very welcome in their homes and were not seen as a threat to care or the family; quite the contrary. Insurance made new yet always contested divisions of responsibility possible.

Notes

1. The forms of relational care that she distinguishes are 'caring about', 'caring for', 'caregiving', and 'care receiving' (Tronto 2015, 4–7).
2. On how these compensations relate to dignity and moral damage, see Bähre (2023).
3. On insurance and calculability, see also Hoyweghen (2014).

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