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Masculinities in Brazil: Identity tinkering and dementia care

Annette Leibing and Cíntia Engel

Two vignettes – one about a husband who is looking after his wife, the other one about a son caring for his mother – lie at the centre of this chapter about dementia care in urban Brazil. The first narrative especially explores family dynamics around male dementia care, while the second one focuses on interactions in the clinic. And although at first glance the genderedness, as well as the cultural context of these stories, seem to be at the forefront, we argue that both categories need to be seen as changing signifiers. Within the complexity of everyday life, gender and culture are entangled with multiple and co-existing value-systems, materialities, health economics, geriatric epistemologies, personalities, questions of class and biology, and so much more. In other words, the specific Brazilian context and the gendered aspects of care play sometimes more, sometimes less a role as the stories unfold. Our focus nevertheless will be the gendered vectors – contributing forces – within the wider context of care dynamics in the two vignettes. However, thinking about gender in a specific context means a constant repositioning and identity tinkering – even in Brazil, where often the predominant image of the ‘*machista*’ (male chauvinist) is evoked in describing local masculinities (see below).

Vignettes are incomplete narratives – they are glimpses of lives embedded in a fragmented context, but in which, ideally, concepts emerge that capture important and revealing aspects of what is at stake. Such concepts – for instance ‘family insufficiency’ – are analytical and necessary short cuts to complex social phenomena. Our vignettes obviously only provide a faint image of what it means to care for someone with dementia, which is a multilayered compound of activities and dispositions, and this is especially so in Brazil: the

country is often perceived as highly complex and – a metaphor used at least since Bastide's classic description of Brazil from 1964 – a land of 'contrasts'. Educator Paulo Freire, for instance, described Brazil in 1998 as, 'the dramatic coexistence of different times that overcome together in the same geographical space – backwardness, misery, poverty, hunger, traditionalism, magical conscience, authoritarianism, democracy, modernity, and postmodernity' (quoted in Steinberg 2011, xxi). The same complexity can be found when talking about gender, where different historical times and concomitant value-systems co-exist – a fact that might at least partly explain the tensions found in the vignettes we will discuss in this chapter. Heilborn and da Silva Cabral (2013), in their study of young Brazilians, gender and sexual practices, come to the conclusion that notions of gender equality, even in more educated parts of society, are less commonly accepted and put into practice by men as compared to women. The authors write that:

highly educated men demonstrate a weak adherence to the principles of gender equality, while their female peers show a remarkable flexibility in their attitudes toward and beliefs about sexuality. This unexpected disparity provokes us to suggest that there is a reinvigorated expression of gender inequality in a social stratum, in which the real progress of egalitarianism could easily be imagined.

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More specifically speaking about gender, old age, and self-care, Coelho, Giacomini and Firmo (2016) show that in their study, most men – just like in other national contexts – avoid the topic of medical care, and link illness, as well as the ageing body, to frailty and a loss of masculinity. Male self-care, like elsewhere, is typically enacted through practices of care outside of the health domain, although such activities – playing sports, sexual activities, or physical work in general – can get medicalized, when declining functionality is perceived as pathological (Katz and Marshall 2003; Leibing et al. 2014; Medeiros et al. 2014; Pereira 2009). This avoidance of medical care needs to be seen as partial and paradoxical, and as in co-existence with a generalized Brazilian fascination with health technologies and especially with pharmaceuticals. This major phenomenon in Brazil we have called elsewhere 'pharma-literacy' (Leibing, Engel and Carrijo 2019).

One way of 'rejuvenating' old age through a hybrid – both extra- and intra-medical-domain kind of self-care – is well described by Debert and Brigeiro (2012). Already happening before, but especially after the introduction of Viagra to the Brazilian market, a major 'eroticization of old age' took place, with a concomitant quasi-obligation – more for men than for women – of talking constantly about and ideally also having (heterosexual) sex in order to continue to inhabit the universe of younger adults. Brigeiro (2000) introduces in his study a category that was frequently employed by the middle-class urban men he studied in Rio de Janeiro, 'the pyjamas'. Different from the men Brigeiro observed and who regularly met in public spaces, a man described as a 'pyjama' is someone who is passive and who stays mostly at home (imagined as wearing pyjamas and slippers); he is pitied, and perceived as dominated by his wife.

The adherence to such masculine values suggests that adopting the role of a caregiver for a Brazilian man is not always easy, although a number of studies, as well as our own observations stemming from extended fieldwork, also portray men who apparently have accepted (and enjoyed) such roles. However, as Santos and Rifiotis (2004) argue, Brazilian men generally can rely on more help from other (mostly female) family members when compared to women as caregivers. Further, the Brazilian institution of the maid in the middle and upper classes plays an important role in the capacity of caregiving, although less so in the following two vignettes. And although the affordability of the *empregada*, the maid, has changed in recent years as a result of stricter labour laws, the still very common and poorly paid household help is an important element in Brazilian cultures of care (see Vilela 2019). These women help to keep older people in the community, while (relatively uncommon) institutional nursing homes carry an extremely negative connotation of abandonment. The role of the maid as care aid is increasingly shared with the more recent phenomenon of trained professional caregivers, *cuidadoras*. The growing need for these mostly female professionals who get hired by families, as well as mushrooming public and private training programmes all over Brazil, shows the strong reliance of the State on families to be responsible for caring (and paying) for their ageing persons in need (Debert and Oliveira 2015). In the first vignette, the family had hired a *cuidadora* who helped with some of the daily caregiving tasks, while in the second narrative, the sister who lived in the same building, sometimes sent her *empregada* to help with household chores.

The lack of a solid social net in Brazil is, of course, especially difficult for poorer families, in which, additionally, the ideal of the ‘provider husband and father’ is often absent (de Souza 2009). The documentary *Alzheimer na Periferia* by Brazilian filmmaker Albert Klinka (2018) describes with a lot of sensitivity how five families, living on the outskirts of São Paulo, deal with the many challenges and the lack of resources they face in caring for a family member with dementia. The moral obligation to care, based on Christian family values, is a strong motivating factor in the stories narrated in the film.

Finally, most masculinity studies nowadays show that something like an ‘identity tinkering’ takes place regarding male caregiving – as a result, most current work insists on the fact that there are gendered aspects, but that they are much less normative than they were in the past. As an example, Calasanti and Bowen (2006) describe in their work, which took place in rural UK, how caregivers constantly crossed gender borders – a fact that can also be observed in the following two vignettes.

1. Vignette one: Caring for his wife

In 2018, Mr João turned eighty. He was born in a rural area of the northwest region of Brazil, as was his spouse, Mrs Aparecida. They got married in their twenties. Before that, Mr João was married to another woman and had three children. With Mrs Aparecida, he had seven children, six girls and one boy. In the 1960s, they were raising their children together, with the resources of the farm where they lived. But when Mrs Aparecida got pregnant with their last child, Mr João decided to migrate to the Federal District, where the new capital Brasília was being constructed and where workers were needed.

Mr João’s father went first; he sold almost all his lands for a negligible amount of money, believing in a propagandized promise of a ‘better life’ in the Federal District. Mr João decided to do the same. He stayed for almost three years in the Federal District and saw his father come to regret not having his land anymore and having to live and die in a landscape that he could not love. But he also saw his brothers building their houses and bringing their families to live in the Federal District, where urban life was progressively appearing to provide better opportunities to study and work.

During those years, Mrs Aparecida stayed in the north-western part of Brazil and took care of their children, with the help of her family. She also started to work as a seamstress, because the money that her husband had been sending to her was not enough. She almost lost her last child in a fire that occurred in her home. Mr João did not return home to help with this crisis. Her family discovered that he had started a new family in the Federal District. But, with some insistence on the part of Mrs Aparecida and her family, he finally returned to the north-western region. They moved to the capital of a nearby state, not far from the farm, and they stayed together for many years – a period in which Mr João was described as having been a good provider, but a very strict father.

In 2000, by which time all their children were adults, Mrs Aparecida became more and more forgetful. One day, she got lost on her way home. The daughter who was still living with them took her to a doctor and, after a lot of tests, Mrs Aparecida received the diagnosis: Alzheimer's disease. At first, Mr João became her main caregiver, with the help of his daughter and a domestic worker. Just like many other husbands of women with dementia of his generation, Mr João had to learn how to deal with caring activities, something that he had never been responsible for before (cf. Santos and Rifiotis 2004). But differently than other experiences that we and other researchers have learned of (Russell 2001; Baker et al. 2010; Robinson et al. 2014) in which the husband engages intensively and almost exclusively with caregiving, Mr João did not fully adhere to being a caregiver.

One of the reasons, his daughters observed, had to do with the fact that Mr João had never been perceived as a caring husband. The daughters described him as verbally aggressive, a '*machista*'. And there was a lot of bitterness resulting from the fact that when he went to another state to pursue a better life for his family, he started a whole second family and did not provide as he had promised. The daughters were convinced that he would be a bad caregiver for his wife. Therefore, the four daughters who were living in the Federal District decided to take care of their mother there. They separated the couple. Mr João said that he would prefer being with his wife and have the daughters moving there to help him. But realizing that this option was not economically possible, he finally agreed to the decision.

That did not work very well. Mrs Aparecida wanted to be with her husband. She started to cry repeatedly and became more and more agitated. The doctors

then prescribed her an antipsychotic drug, in order to deal with this 'agitation.' The drug did not work, so the daughters decided to bring their father to stay with Mrs Aparecida. And that worked: she became calmer and happier with her 'old man' (as she used to refer to him), even when dealing with his yelling.

However, although Mr João initially agreed to move, he quickly realized that being in this new place was not what he wanted. He remembered his father's fate regretting moving, and he missed his friends. His relationship with his daughters was complicated. He was being cared for – just like his wife – but he didn't have a strong voice in decisions. This was made even more dramatic when he became blind due to complications from cataracts.

The same geriatrician was attending both he and Mrs Aparecida. Initially, the consultations were provided together. And although Mr João tried very hard to convince this geriatrician to engage with his version of daily life and of what he thought his wife needed, he was constantly ignored by the geriatrician, and his way of seeing the situation was contested by his daughters. For that reason, the geriatrician decided to stop seeing them together and separated the couple one more time. Mr João was classified as a '*machista*' – a term that doctors used when discussing his case and it was even found in his patient file. According to the doctors, he didn't have the best interests of Mrs Aparecida in mind. Mr João also started to complain about the doctors that were attending him in the Federal District. He let everyone know that he was there against his will and that he was alone and disrespected – not treated as 'the man he was.'

But although he did not stop complaining about his wife's disease, and, sometimes, was irritated with her, he learned how to communicate with her like no one else. One day, one of the daughters was trying, with no success, to convince Mrs Aparecida to take a shower. She was very irritated with the situation. Mr João approached his wife and said: 'I've just enjoyed my bath; the water is warm and delightful. Are you going, too?' She grabbed her towel and said: 'I'm going to take a shower, too.' The daughter at this point told me that her father helped a lot with daily care, so despite the fact that she considered him responsible for some daily distress, she also believed that he was an important part of caring for her mother. It's 'complicated', she said. For that reason, they were also insisting that it would be important for him to stay there and Mr João repeatedly used the argument, 'she is my wife, and now she needs me'. But sometimes he became sad and mad about his destiny: 'I'm stuck,

this is no life for me, she was such a good wife before, now she is like that! I'm paying for my sins from the past'.

In the Federal District, other relationships with the wider family – the daughters' husbands and the grandsons – also became part of the intricacy of daily care. These caring activities revealed further aspects of the expectations and norms regarding masculinity, especially that of the younger men. Although there were four daughters living in the Federal District, three were more involved in managing the division of care: Marta, Julia, and Joana – all in their forties. Joana was divorced and, because of that, she was chosen as the one that would live with their mother and father. Marta and Julia used to visit constantly and, some days of the week they took Mrs Aparecida to stay in their homes. Joana told me that her sisters insisted that as she didn't have a husband, it would be easier for her to share the house with their parents. She loved her mother very much and was happy to take care of her, but she was ambivalent about her sister's argument. She observed that a husband could be a complication in caring for the elderly, but also an important partner. On several occasions, she came back to this point when comparing her sisters' husbands.

Marta's husband used to be evaluated in the family as a caring and 'good' husband. He was a strong provider but was also really engaged at home. He used to do some of the daily home care, but a major contribution of his was that he took over transportation to doctors' appointments, as well as solving the multiple bureaucratic needs of the family. He was very attentive when talking with Mrs Aparecida and she liked him, and, his best characteristic: 'he does not get in the way'.

Julia's husband, on the contrary, was known as the one that 'gets in the way'. That meant that he would limit his wife's attention given to her parents, would complain that she did not take enough care of her nuclear family, because she spent a lot of time with her parents. Mrs Aparecida clearly showed that she did not like him, and neither did Mr João. They felt he had repeatedly mistreated them. That situation would compromise the time that Julia would put into caring, as well as the trust of the other sisters regarding Julia's care work. This aspect – that it is the couple that influences how Julia, as an individual, is able to care – is rarely discussed in the literature (although there are many studies on couples in which one of them is the person with dementia). Here, Julia's relation to her husband is central in the evaluation and division of care. We

found this distinction between a 'good' and a 'bad' husband in other contexts as well.

In fact, caring for older parents with dementia was a constant source of debate and reflections about masculinity itself within this family. The constant references to types of masculinity, but also possible implications for sexuality were important topics of discussion, and especially when the care of grandsons was required, but also questioned. Marta's son, who was 18 years old at the time, was very close to his grandmother. When she was at his house, he would help his mother with the care work. He showed a lot of interest in his grandma's disease, and did Internet searches about Alzheimer's that he discussed on several occasions with his aunts. His interest became an essential part of the care work, because every time someone needed information, he would be able to find an answer on the Internet. He would refer to himself as a 'dedicated son', one that would always engage with his parents.

While on one hand he was considered a 'good boy', especially for his attentive way of relating to his grandmother, on the other hand some family members doubted his straightness: care and masculinity became evaluated in connection with an ambiguous sexuality, especially in young men. Joana once told me that she never let her sons (both in their twenties) do domestic chores or activities of caring when they were children because she had been taught that this could compromise the making of a straight man. She believed that this was one of her main responsibilities as a mother. In 2018, though, she told me that she was regretting that a little bit; she was feeling that her sons were not very open to helping at home, that times had changed and she said this even though they were close to their grandma. And she also thought that they were just like their grandfather and father in one problematic aspect: they were '*machistas*'.

One of those young men once told me that he didn't know how to do some things, he didn't feel prepared, although he wanted to help. The other one explained that he, as a man, did not have the body built for care. It would be humiliating for him to try. They had different perspectives about why they didn't feel that they should or could help. One was more convinced that a lack of experience was at the core of his inability; and the other one believed that it was because of his male body not made for care. Both preferred to help their mother and grandma with money – in the context of the families' limited budgets, an aspect of care that was much appreciated.

2. Vignette two: A follow-up consultation at the geriatric clinic

It was a day at the specialized out-patient clinic in Brazil's Federal District, when mostly individuals with a dementia were seen. Following the established protocol, a second-year geriatric resident would start the detailed consultation, and a more senior geriatrician would join towards the end of the session, in order to discuss the medication regimen the resident wanted to prescribe.

The resident called out the name of Mrs Madalena, who was sitting in a wheelchair in the waiting area. We all entered one of the tiny cubicles in which the examinations take place. The small space was now packed with a desk, behind which the resident took her place, the chairs for the three sisters who accompanied their mother, and Mrs Madalena's wheelchair, while Mrs Madalena's son sat with me, the anthropologist, on the examination couch. Through the barred windows we heard birds in mango trees in the patio, and through the open door of the cubicle a cacophony of voices from the other examinations taking place, only separated by thin walls made of white varnished panels.

The son beside me looked at his hands, while the cheerful voice of the resident asked Mrs Madalena some questions about her well-being that were either not answered or were answered with grumbling noises. The young geriatrician scrolled through the thick patient's file and then turned to the sisters. In a more matter-of-fact tone, she asked the three women about what had been going on since the last consultation. What followed was a long discussion of each medication Mrs Madalena was taking and of several symptoms – from sleep to bowel movements (for more detail, see Leibing, Engel and Carillo 2019):

Dr C. How much are you giving?

Daughter As you wrote it down: at 4 pm give one [pill].

Dr C. Of 25 [mg].

Daughter Of 25; and at night one of 100, around 9 pm and ...

Dr C. (surprised) Ah, you are giving a whole of 100 or ...?

Daughter Yes, a whole one. With that she sleeps all night.

Dr C. Who is giving the medications? She lives with your family?

(...)

Once again, I was astonished by the technical details in a conversation that sounded sometimes like doctors talking among themselves, and not like a geriatric resident speaking with a family member without medical training. Another example:

Dr C. The Hidrocloro is a diuretic, before it was the Moduretic. (...) That's because the Moduretic was a combination of amiloride with hidrocloro, so I changed it, because now she is only using the Hidrocloro.

The resident then turned to me and explained that the diagnosis was 'probable Alzheimer's disease' – probable because of the many other comorbidities. It is 'the cowardly disease', commented one of the daughters, in the sense of a coward who is attacking someone who cannot defend herself. She explains: 'she [my mother] was so vain, so beautiful, always so very well dressed, nails, pedicure – even at home. And now this.' The daughter adds that she found her mother playing with her faeces on several occasions.

The son, sitting beside me, had stayed quiet for almost half an hour, in a serious and introverted mood. Then he spoke for the first time:

Son She is sleeping all the time.

Dr C. That was after we readjusted the medications?

Son Yes. There are days she lies down, doesn't even take the meds at night, so I try ... ahm ... But when she is a little more awake, I put a little bit of perfume on her, so she feels good about herself.

The old woman: screams [and says something unintelligible.]

Up to this point two aspects of Mrs Madalena's care stand out – the central role medications play in Mrs Madalena's care, and the silence of the son – two factors that are interlinked in this narrative.

Medications

As in most consultations, medications play an important role in 'fine-tuning' Mrs Madalena's symptoms through a constant adaptation of dosages and types of pharmaceuticals, but also of circumstances: when families are perceived as having limited capacities of care, tranquillizing and the controversial antipsychotic medications are prescribed in higher doses than in families that

are perceived as well-functioning in terms of caregiving. The geriatricians we interviewed were aware of the dilemma and deplored the situation, but said that sometimes they had no choice (see Engel 2017; Leibing 2009). The informal diagnosis of ‘family insufficiency’ was regularly used by health professionals to circumscribe this lack of care capacity, where then medications were prescribed to counterbalance symptoms that would otherwise disturb even more greatly the fragile equilibrium at home, such as being awake at night. However, Mrs Madalena was now sleeping too much. Dosage and, sometimes, type of medication needed to be adjusted. It seemed that at a previous consultation the resident at that time had augmented dosages, because of the severe tensions the family was experiencing, fuelled even more by the financial issues caused by the one brother who was distrusting the caregiving son.

Medications in this context can be seen as bio-social objects – objects (e.g. pills) that not only alter Mrs Madalena’s biology (like blood pressure and synaptic connections), but that additionally alter – or are altered by – social relations. As an example, pills are prescribed for calming too agitated patients, and therefore relieving family tensions. In the case of the caregiving son, augmented dosages are based on the geriatrician’s perception of a family conflict resulting in not good enough care: this can be based on the opinion that a son is not a good caregiver, lacking caring attitudes of work seen as typically female, while higher doses might also follow one brother’s logic, that the son lacks care skills because his primary interest is his mother’s money and not her well-being (see below). Finally, medications and medical technologies also impact on the relationship between families and the State, when, for instance, certain medications and geriatric diapers are distributed for free, sometimes linked to promises made by politicians and playing a major role in some elections, in which several politicians were elected over the last thirty years, based on their programmes targeting older people.

The silent son

A second important factor is the astonishing exclusion of the son during the consultation. From the beginning, while the very long discussion about each of the multiple medications took place, the daughter answered the resident’s

question about 'Who is giving the medication? She lives with your family?' with: 'No, although we live in the same building; she lives with G. [the son who is sitting beside me]. He recently went to the Public Defender, but it is so complicated . . .' The daughter then explains that the unemployed son is trying to get custody of his mother, so that he can have access to her bank account with her small pension and pay the daily expenses, but one of his brothers is trying to prevent that, arguing that G. does not want to work and is only after his mother's pension. And although now it is clear that the son is taking care of his mother in her apartment, the discussion of the care regimen continues with the daughters; the male caregiver gets ignored, until the moment when long into the consultation, he speaks up and observes that the new medications made his mother sleep too much. At this moment he still speaks softly, almost timidly, but gets increasingly agitated.

The son complains about the lack of recognition he receives for his dedicated work, because some of his siblings and, especially one brother, were accusing him of having an easy life and of merely wanting his mother's money. He describes in detail what he called 'sacrificing myself': the difficult, never-ending, and sometimes disgusting, work he has to do – traditionally female work – that goes unacknowledged by his family. His voice gets louder and he becomes more and more agitated, while other residents and one of the senior geriatricians start entering the tiny room to try to calm him down. The son starts to cry. After this episode, the son was prescribed an anti-depressant.

3. Care and recognition

The two vignettes provide a picture of different generations of men engaging with dementia care and how such care work is performed and evaluated with regard to male identities. Caring, with its female connotations, deeply unsettles the men's identities: at stake is the authority of a father, husband, and former 'head of the family' now facing the disregard of daughters and doctors and doubt about his abilities as a caring husband. An adult man, a son and full-time caregiver encounters distrust because he needs the pension money of his mother. Further, there is a son-in-law who is classified as 'good' or 'bad', depending on how much time he demands from his wife. Finally, a young man,

a grandson, is being investigated about his sexual orientation – if he is too caring, he is suspected of being gay – while at the same time not caring enough means being classified as potentially ‘*machista*’.

In fact, there are various kinds of masculinity being disputed in these encounters that vary depending on the generation, but also on conflicting images of what it is to be a man. One could speak here about a culture war – a battle around the intertwined different value-systems and personal and national ideals of manhood, constantly nurtured by, public figures, soap opera characters, churches, celebrities, jokes, resulting in more or less embodied values. Progressive values that question rigid, traditional masculinities are part of this mix, and some values even come to be regretted, for instance in the way to raise a boy, because, as one interviewee explained, ‘times have changed’. At the same time, the two narratives reveal how an extremely conservative view of gender rules and sexual orientation is interacting with more progressive perspectives. As shown in many more recent masculinity studies (e.g. Boratav, Fisek and Ziya 2014; Scheibling 2020; Santos and Rifiotis 2004), Brazilian men also adhere to multiple masculinities and negotiate maleness within care work. In our two vignettes, men and women compose narratives in which there is a tension between the desire to increase men’s caring side, while trying equally to avoid creating too feminine behaviours, within a strong homophobic paradigm.

One specificity here, compared to most of the literature on masculinities with an evolutionary perspective (showing a transformation of rigid role models to more fluid ways of conceiving gender over time,) is that in some parts of the Brazilian population in the last years, values bound to ideas about masculine ideals are actually getting more conservative. In fact, after a progressive government in Brazil under presidents Luiz Inácio Lula da Silva (2003–11) and then Dilma Rousseff (2011–16), in which male identities became more attuned to greater equality in gender roles, including a greater tolerance towards the blurring of gender boundaries and LGBTQ+ identities, the present government celebrates male identity as ultra-traditional, supported by the enormous movement of fundamentalist evangelical churches with their strict heterosexual role models. In fact, one reason often heard by voters for their admiration of the current president, Bolsonaro, is that the sacred image of the family was ignored by the former government, a critique that strongly

relates to sexual identities. The recent exclamation by president Bolsonaro that Brazil is a 'land of *maricas* [effeminate persons, sissies]',¹ referring to the fear of Brazilians preoccupied with uncontrolled Covid-19 numbers in the country, shows the denigration of men who care too much about health, as well as the ideal of toughness, strength and carefree attitudes towards health associated with 'real' maleness.

Our reflections on the topic are only a first step: ideally, accounts of masculinities should be longitudinal, in order to see how cultural change reflects on identity tinkering and practices of recognition. What we can affirm is that looking at how masculinities are performed in dementia care can open up complex reflections on sometimes contradictory national and generational perspectives of what it is to be a man and how people deal with these questions on a daily basis.

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¹ Quote (our translation): 'I am sorry for the deaths, but we all have to die one day. There is no sense in fleeing from this [Coronavirus] reality, we have to stop being a country of *maricas* [sissies]'. (Folha de São Paulo, 10 November 2020; <https://www1.folha.uol.com.br/poder/2020/03/veja-o-que-bolsonaro-ja-disse-sobre-coronavirus-de-certa-histeria-a-fantasia-e-nerouse.shtml>)

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