Debating dementia care logics

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Although around the world Brazil’s image is of a youthful nation, population aging is happening there in a highly accelerated way: currently there are more than 28 million older Brazilians (IBGE, 2020). The soaring number of people with dementia has become a major public health problem: Brazil has one of the highest prevalence rates of dementia in the world, reaching a mean of 7.6 percent (Prince et al, 2015). Dementia care is extremely challenging, especially considering that in Brazil care happens mostly at home, making families responsible for their older family members’ well-being. Care resources (home care, medications, housing infrastructure, and so forth) are widely lacking (Burlá et al, 2013), except for richer as opposed to poor people. Without a well-functioning social net, most Brazilians rely on a ‘patchwork of care’—a notion that describes uncertain and ongoing negotiations required of people so as to be able to provide care—the tinkering of individuals mobilizing multiple sources of help, on which they cannot always rely (see Leibing et al, 2016).

How can this complex landscape of care be captured methodologically? Based on ethnographies carried out in a Brazilian metropolis—the Federal District—we propose focusing on ‘logics of care’ in order to get closer to what is at stake in care work. Here we follow Annemarie Mol (2008), who claims that processes that involve care have their internal logics and that we can approach them by observing—from concrete situations—what is done in the way of care. Alternatively, as proposed by Pols (2015), we look at the intra-normativity of these practices, what is considered good care and what is understood as a challenge, dilemma or as negative practices. More concretely, by juxtaposing two ethnographies of dementia care—one situated in a geriatric outpatient clinic, one at home—our aim is to show that the two logics that emerged from comparative fieldwork are at the same time distinct and specific but also interconnected.

In the first ethnography, care is provided within the public health system—the Sistema Único de Saúde (SUS)—by a multidisciplinary team.
This kind of care is based on what we want to call the ‘ensemble logic’. The second case, which we describe as homecare, shows how care is carried out in households based on what we call a ‘routine logic’. The terms ‘ensemble’ and ‘routine’ are emic terms borrowed from our interlocutors. They do not represent obvious and unified meanings, but they lead us to dialogue comparatively with the reflections of our interlocutors and how they define what must be done to provide good care.

We also do a comparative exercise in relation to the two logics of care. We monitor what are the main problems and how these problems are situated in both logics, how they influence action and value systems. We pay attention to the fact that the logics are interrelated, not restrained to one ethnographic setting, and therefore deepen our understanding of situated dementia care, but equally enlarge debates by providing data that is lived and debated from different perspectives. Mol’s notion of a ‘politics-of-what’ is helpful here: ‘A politics-of-what explores the differences, not between doctors and patients, but between various enactments of a particular disease’ (Mol, 2002, p 176). And although one of our ethnographies at first sight is about doctors and one is about patients, what is at stake here is the ‘distinct complementarities’ found in the complex processes and technicalities of care. We finally combine this with the notion of ‘care ecology’ proposed by Das and Das (2006) and Das (2015) in order to think about the articulations of places, specialties, prescriptions and ways of using medicines—and about how responsibility is assigned for what goes wrong.

Care is not a simple or obvious term for anthropologists who study dementia. For this chapter, we understand care as a type of practice that engages a multiplicity of elements—technological, economic, technical and affective—and that involves decision-making processes and the constitution of a variety of skills: it means ‘persistent tinkering in a world full of complex ambivalence and shifting tensions’ (Mol et al, 2010, p 14). As stated by Pols (2015), such a perspective radicalizes the relationality of care, because acts of care cannot be reduced only to questions of dependency and power. In addition to being a practice with particular logics and normativities, we also understand care as a process that unfolds alongside political, economic and health infrastructure issues—all of which are included and articulated in the practices. As Thelen (2015) would say, care can be understood as an open-ended process, directly connected with social organization or, as Das (2015) suggests, relying on local ‘care ecologies’ (Das, 2015) that add to the bigger-picture vectors, like places, people and policies of care.
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Comparative ethnography

The data discussed in this chapter come from a comparative ethnography carried out by one of the authors, Cíntia Engel. The study formally lasted one year and six months and was divided into two main research circles, which maintained intense dialogue with each other. For nine months, the researcher observed, conducted interviews, read medical records and followed the clinical routine in the multidisciplinary geriatric centre of a university hospital. It is a centre of excellence (located within a public university hospital) and specializes in the treatment of dementia. The centre was chosen because it is a place that combines the function of assisting patients with training professionals, and its senior geriatricians are involved in knowledge transfer and even policymaking at the local and national levels.

For another nine months, Cíntia visited the homes of three different families, following their daily routines—their processes of making food and cleaning the house, their ways of caring and consuming medicines—and moving with them through health centres, pharmacies, consultations with different doctors and interactions with neighbours, friends and relatives.

We opted for narratives of two ‘typical’ cases from each context. Our intention is not to debate the particularities of each case, but rather to constitute a description that brings us closer to the articulations, the processes, the type of logic that connects several experiences that emerged in the field. As already mentioned, we work with two emic notions to help us in this comparison: the ‘ensemble’ and ‘routine’ categories.

‘Ensemble logic’: care at a specialized public geriatric unit

One of the first expressions we heard in the field referred to the fact that, when taking care of someone with dementia, it is necessary to pay attention to the ‘ensemble’ (o conjunto). Many people arrived at the geriatric health unit with multiple health problems—the cases they attended, doctors told us, were complex. And although, as we will see, a major part of a treatment involves medications targeting specific symptoms, health professionals are very aware of the circumstances, the big picture—or the ensemble—that includes the socioeconomic situation of each family. We decided to call this type of approach the ‘ensemble logic’.

The ensemble logic doesn’t only involve the recognition that patients’ health conditions are complex; there is also an attempt to
deal with this ensemble of problems through ongoing discussions around reading multiple signs and proposing various interventions that are easily questioned and adjusted when the bundle of (physical and social) symptoms shift due to pathological, pharmacological and social circumstances. Ultimately, as we will see, treating the ensemble is to stabilize relationships.

Mr João arrived at the centre already diagnosed with Alzheimer’s disease in an intermediate phase—between moderate and severe.\textsuperscript{3} Prior to his visit to the centre, he was being treated by two doctors, a private psychiatrist and a public cardiologist. He began to pass out frequently and eventually became more aggressive towards his wife. One of his doctors thought that, given the complexity and variety of symptoms and the large number of medications he was taking, it was best to refer him to a geriatrician.

In a first consultation at the centre, the professionals heard the complaints of Mr João’s daughter and wife. He said little. The daughter mentioned that Mr João was fighting a lot with his wife; he was insisting on having intimate relations with her without her consent and was calling her ugly names. The wife, a lady in her late eighties, was visibly tired, cried a few times during the consultation and reported her difficulties in daily life, especially because of her difficult coexistence with her husband.

Furthermore, what was worrying everyone was the fact that Mr João twice—or three times—lost consciousness and fell, without anyone being able to help him. They were waiting for the results of an exam ordered by the cardiologist to find out how his situation was, given that Mr João had already had heart problems.

Mr João was already using some medications: donepezil\textsuperscript{4} and memantine\textsuperscript{5} to treat Alzheimer’s disease; clonazepam\textsuperscript{6} to help him sleep at night; citalopram,\textsuperscript{7} an antidepressant, because Mr João had complained about being sad as the result of being sick. Additionally, he was taking two drugs to deal with his heart condition.

In this consultation, without having the results of the examination on the cardiac condition, the geriatricians decided to stop the clonazepam. The geriatric doctors disapproved of the use of certain drugs, which, following guidelines from the Ministry of Health, they conceived of as ‘unsuitable for the elderly’, including clonazepam and some antidepressants, such as fluoxetine and amitriptyline. But it was very common for people to arrive at the centre having used those drugs for years and resistant to giving them up.\textsuperscript{8}

The doctors explained to Mr João’s wife that his actions were not ‘malice’, that they were part of the disease process. They offered the
wife the chance to participate in a group of caregivers, where she could discuss her problems and ‘accept’ this new condition of her husband’s. Mr João’s daughter, however, explained that her mother knew that the problems at home were related to the disease, but knowing would not prevent her being tired and upset. In addition, she had severe mobility problems due to osteoporosis and it would be very difficult for her to go to the groups alone, while the daughter and her brother could not miss work to take her by car.

In such groups we observed that, similar to issues raised in caregiver groups abroad, members are informed about how the disease develops and tips are given on how to deal with daily life. An important recommendation is to follow a regular routine, avoiding conflicts and not pointing out forgetfulness or mistakes to the person with dementia; it is equally important to create spaces of rest for the caregiver, including by their asking for help with daily activities. A central idea at the centre was that by establishing good care relationships it is possible to improve daily life, which then positively influences the treatment and eventually leads to slowing down the decline due to dementia. The treatment, then, targets to a great extent the care relationship. Medications are not only meant for cognitive impairment: treatment depended a lot on good home care.

In the case of Mr João, the health team decided, in addition to counselling on how to care for and deal with daily life, to prescribe an antipsychotic, a controversial intervention because of the risk of serious side effects. The justification given by the prescribing resident was that ‘the family was suffering’ from Mr João’s behaviour. The team also called his wife for an individual appointment, arguing that she was ‘burdened by care’ and that she also needed to take care of her own problems, such as osteoporosis and several other health problems. ‘Burdened by care’ is a category that gained diagnostic status at the centre. It is understood that, if the responsible person becomes overloaded, they can get sick and be unable to provide good care. The antipsychotic, therefore, did not only target Mr João’s body; it became a medication prescribed to help the husband and wife coexist, so that care at home could be improved.

At a subsequent appointment, the geriatrician looked at the cardiac exam and noticed that Mr João’s heart rate was alarmingly low. In a team meeting, the health professionals then debated whether the drugs prescribed for dementia could be responsible in part for the cardiac problem. All these drugs slowed the heart rate, and became riskier when prescribed in combination. As one geriatrician explained, antipsychotic drugs might interact with one of the drugs for Mr João’s
cardiac condition. Thus, the drug treatment that was supposed to reorganize the family dynamic was interfering with Mr João’s treatment for his heart.

In a debate about what to do, one of the doctors suggested cutting all dementia drugs and focusing only on the heart condition. Another doctor, however, was concerned about family relationships and the health of Mr João’s wife. The wife’s condition could worsen and, if she reached her limit, perhaps Mr João would be left without any assistance and could be admitted to an institution—a last resort solution for most Brazilian families. They ended up cutting most of the dementia drugs and the antipsychotic drug, believing that the danger in maintaining them was too high.

The team considered that if the wife lost her ability to care, one of the children would have to take over, or would still have to hire a private caregiver. The centre’s social worker was called in to mediate the situation. The social worker’s function was as much to convince the children to participate more often in daily care as to guide the family in looking for all the benefits provided by law to help with the family’s expenses. In this way, they would avoid another category that was used at the centre like a diagnosis: ‘family insufficiency’. This term would be applied when a family was unable to share care among its members or when there was not enough income for hiring a professional caregiver. In consultation with Mr João’s wife, the team decided to prescribe an antidepressant for her, imagining that this way the couple’s life together might improve.

We want to draw attention to some points which stand out with respect to Mr João’s care. The ‘ensemble’ includes everything, from drug interactions to family relationships. Geriatric care, even when only based on medications, is therefore a relational mode of care. Ideal care here involves an emotionally stable primary caregiver, a large family engaged in care, financial resources to hire professional caregivers (in order to put less pressure on the family) and the use of properly administered medications. However, such an ideal constantly runs up against a number of challenges.

One challenge, for example, arises when an overburdened caregiver insists on more medications for the person with dementia. Another is that a family may not organize itself in the expected way: conflicts occur, and siblings might even end up in court. Another is that medicines can cause unwanted effects, accrue high costs, or there might be difficulty attaining them at a nearby pharmacy, thereby undermining good care. For all these reasons, treatment demands constant corrections and adjustments of doses but also of relationships,
what we call elsewhere ‘a constant fine-tuning’ of drugs and relations (Leibing et al, 2019).

This type of geriatric therapy depends largely on a counterpart from families and caregivers being involved, and older people without families are rarely seen at the centre. Geriatric treatments depend on family members constantly observing the uses of medications, on their knowing how to report good and bad effects, on chasing after exam results, on pushing against bureaucracies to access rights to get free medications, on organizing family care. It is this counterpart that we will talk about in the next section, but from another perspective: that of families caring at home.

*Establishing and maintaining routine: care within households*

At home, a fundamental category used by the research interlocutors to talk about care was the ‘routine’. Phrases such as ‘You have to get the routine’, ‘It got in the way of my routine’, ‘I miss our routine’ were common sayings. The use of the term routine, however, has a specific meaning. It is different from routine used in the caregiver groups, where a common recommendation is always conducting the same activities at the same time of the day—something that provides a feeling of security and orientation to those living with dementia. It is also different from what is usually called routine when talking (critically) about care in institutions: standardized and rigid organizational ways of caring (Kitwood, 1997; Chatterji, 1998).

To some extent, the elaborations of the interlocutors about the routine relates to the idea of managing everyday life, or daily life, as elaborated by Pols et al (2018) and by Das (2015). Routine is an intense space of reflexivity, testing and adjustments. Or it can also mean, as we have learned from our interlocutors, a certain rhythm of the days, weeks and months that allows for organization—without major disruptions—of the handling of multiple relationships, doctors and medicines, of time spent on public transport and of the ability to pay for most care expenses.

Establishing and dealing with routines is not a state of regular repetition; it is rather a constantly changing and intense challenge that involves reflexivity, experiments and adjustments. It involves engaging people, family members, neighbours—even the researcher—on a daily basis: a patchwork of care.

Mrs Aparecida, an eighty-year-old woman who lived in a city around the Federal District and who had lived with Alzheimer’s for seven years, started experiencing some loss of consciousness. The first few times, her
daughters took her to the emergency room of a public hospital near her home. On these occasions, doctors, when measuring Mrs Aparecida’s blood pressure, noticed that it was high and prescribed her a medication to lower it. However, on one of the days when Mrs Aparecida was sick again and went to the emergency room, a very young doctor decided that she had labyrinthitis and prescribed a medication for this condition. After taking the medicine, Mrs Aparecida became very ill. First she was agitated, then drowsy, and complained a lot about her malaise. The family decided to stop the medication. Mrs Aparecida was supposed to have an appointment with the geriatrician, but not for another three months. So the family looked for another doctor, a family doctor from the local basic health unit—which is responsible for primary care. This family doctor understood the repeated loss of consciousness as resulting from seizures and prescribed a drug for it: phenobarbital.

One of the daughters, suspicious and resentful after the experience with the emergency doctor, took a letter to the geriatrician’s health centre. The geriatrician, a doctor with a post in a Federal District institution, agreed with the hypothesis about seizures, but decided to prescribe another drug: phenytoin. This medication could be had free in Mrs Aparecida’s home municipality, at the so-called popular pharmacy. However, although this city was connected to the Federal District as part of the wider metropolitan area, it belonged to another Brazilian state, Goiás. Therefore, in order to get the medication in Mrs Aparecida’s home municipality, it was necessary to have a prescription from a doctor that worked there, or at least a prescription made in the same state. They used to solve this bureaucratic imbroglio with the doctor at the basic unit, who took the prescriptions from the geriatric doctor and rewrote them with the forms of the municipality where they lived. The problem in this case, however, was that this doctor did not agree with the change of prescription made by the geriatrician—in his conception the two drugs were ‘the same thing’.

The family ended up buying the medicine prescribed by the geriatrician in a private pharmacy where they had to pay, because when trying the one prescribed by the doctor at the basic unit, Mrs Aparecida became very sleepy. When they finally had the consultation with the geriatrician three months later, they learned that he had chosen phenytoin because it was a ‘preference among geriatricians’: it causes less drowsiness—despite the expected benefits being the same. However, the medicine did not solve the problem of the seizures, which actually increased. After augmenting the dose, Mrs Aparecida became sleepy and disconnected; she looked ‘doped’, as her daughter observed.
Mrs Aparecida used to get very agitated around lunchtime, and she would move things like furniture and household items around—something that bothered her daughters, especially because that used to upset the process of preparing lunch. When they complained about it to the doctor, they received a prescription for an antipsychotic medication. But this medicine left Mrs Aparecida ‘seeing things’. They tried to manage this agitation with still other drugs, but it was difficult, and she was constantly very doped. Observing these situations, one of the daughters complained about doctors and medicines, saying that they could not find a middle ground: they either made Mrs Aparecida very agitated, or very doped. When she was that way, the daughters admitted that they even missed her former state, when she was moving everything around the house.

With time, the daughters ended up creating some strategies for coping with this agitation. They learned to let Mrs Aparecida do whatever she wanted and move things around as she desired—but with supervision. This improved their coexistence. The supervision was oriented toward not letting Mrs Aparecida get hurt. Which was easier to do if two people were around.

This attempt to keep more people at home was a constant challenge. At a certain point this was resolved by hiring a professional caregiver. This external caregiver received her salary from Mrs Aparecida’s retirement pension. One of the daughters, the one who lived with Mrs Aparecida, was unemployed and therefore stayed at home. The rent, food and credit payments were provided by Mrs Aparecida’s granddaughter, who also lived in the house, and from the retirement pension of Mrs Aparecida’s husband, Mr Sérgio—who until now has been absent from this narrative of care. The problem was that he hated living in that city; they came from another region of Brazil, and Mr Sérgio wanted to return, he was missing his home. In addition, his daughters didn’t have a good relationship with him. The crises of coexistence intensified and the solution that the unemployed daughter came up with was that she returned to work. Thus, Mr Sérgio’s income would not be essential for the household anymore.

After some months of job searching, she was hired as a lunch cook at a public school in the region. But then she noticed that the hired caregiver at home was overwhelmed. She realized this only because Mrs Aparecida stopped eating. First, they thought that it could be due to the progress of the disease, but she only avoided meals that were made by the hired caregiver; food made by her daughters was still eaten.

Another daughter, who lived nearby, started to spend more time with her mother. Even with this change, things took time to settle.
This daughter also used to deal with the bureaucracy of the public health system, the SUS: she was responsible for picking up medicines and making appointments with doctors. And that was not a simple job. In order to access all the locations that involved Mrs Aparecida’s care, she needed to take illegally operating vans for transport or arrange rides with neighbours since their neighbourhood had almost no public transport. That was when the researcher became engaged in the ‘routines’ by proving rides with her car.

In addition, there were many other steps and more bureaucracy to overcome in order to be able to make appointments and access medications, not to mention long hours of waiting. Often, entire days were lost just to get one medication. This daughter repeated several times the sentence: “They play with our time!” Having also been responsible for some of the days caring at Mrs Aparecida’s home, it became increasingly impossible for her to manage her time. For this reason, it was not uncommon—even though they could access medicines or other technologies, such as diapers and wheelchairs, free of charge in specific, though far away pharmacies—that they ended up buying them at the expensive pharmacy in order to save time. This private investment involved negotiations and financial sacrifices and the mobilization of more distant family members. And family members used multiple credit cards, running up high debts.\(^9\)

The situation became even more complicated when the doctor at the basic health unit stopped attending. Investments in basic care were increasingly constrained by then-current ultra-neoliberal policies, and he was dismissed. There was no longer a local doctor who would fill geriatric prescriptions, so getting public access to medicines became an even more time-consuming process. Buying drugs at the expensive pharmacy became more common and the family’s debts increased. In addition, the daughter’s contract as a lunch cook was only temporary. Her uncertain future in relation to employment and income meant that further changes would need to be made.

All these highly complex and complicated negotiations to establish a routine were part of taking care of someone with dementia. Providing a more constant rhythm of everyday life was fundamental for Mrs Aparecida’s well-being and for interpersonal relations—on this doctors and family members agreed. Perhaps that is why the term routine was used so often by the family. ‘Getting a routine’, therefore, involved much more than just following a schedule of activities or following learned patterns. It meant constantly trying to create a rhythm that was challenged on a daily basis.
'Ensemble' and 'routine' as care logics

How do these two kinds of care logics relate to each other? We have seen that the ethnographies produced several analytical categories through which we were able to highlight a number of issues that are at stake in dementia care. These categories not only map specificities of home care versus that of a geriatric outpatient unit, they also mirror a strong overlap of the two worlds. This is why a multi-site (or the juxtaposition of more than one) ethnography is so powerful: it is a methodology that is able to highlight interconnectedness—an interdependency of milieus, theories and value systems seen from different vantage points (see also Chapters 7–9 in this volume).

Medications in both worlds are central for good care; they are desired and, at the same time, dangerous objects. They sometimes do not work for the symptom they were prescribed for; they create other symptoms; they change relationships; they require adjustments and intense dialogues with doctors. Both families and doctors expressed doubts and uncertainty on this subject: it is difficult to know what the effect of one drug among many others is and to follow its long-term effects. The dialogue about the effects and the decision to continue or interrupt a certain medication are sometimes even more complex, since they can involve more than one specialist (geriatricians, clinicians and neurologists among others), different levels of action (such as emergency, basic and specialized care) and different perspectives on prescriptions and what symptoms to treat. In addition, such processes also involve dealing with the performance limits of each professional and, above all, building skills to deal with possible divergences.

From the different positions regarding dementia care, the obstacles to what would be 'good care' change. Some challenges cross both logics: excessive symptoms, accumulation of diseases, damage of networks, economic restrictions and instability of drugs in relation to each other all challenge dementia care.

However, these are problems that cannot simply be attributed to one of the parties, blaming, for example, caregivers who do not know how to provide care, do not judge effects well, are not interested in caring or are part of dysfunctional families—which seems to be the strategy of the ensemble logic. This way of looking at problems ends up corresponding, at least partly, to the notion of 'guilt geography' suggested by Das and Das (2006). According to that perspective, some groups, such as, for example, the urban poor, are classified as responsible for the bad use of biomedical technology. That perspective often puts
the guilt exclusively on those groups, although the way that medical technologies are put into practice often involves relationships within the care environment, institutional cultures and even the preferences of doctors for certain prescriptions. From interviews with health professionals we also learned that the government is perceived as guilty in not providing enough resources for good care, and health professionals are therefore forced to juggle two kinds of insufficiency (as well as guilt).

Conclusion

When following the two categories, ensemble and routine, we relate to certain logics of care that are not necessarily opposed, nor are they simply to be analysed separately and then compared. Analysis involves, above all, considering porous relationships and care with tenuous limits. Looking at the logics that emerged in our ethnographies, we rethink and nuance certain truths found in the dementia literature: for example, we are unable to narrate the common opposition between desiring more holistic care and criticize malignant drug care, as is often found among critical social scientists (for example Ballenger et al, 2009; Moreira, 2010; Lock, 2013). We also do not conclude, like some authors do, that biomedical care deals only with the physicality of diseases without considering other factors that mark the daily lives of people and families, often subsumed under the category of care (as a moral obligation) (Kleinman, 1989; Maluf, 2018).

When we, as researchers, opened ourselves up in order to understand the precepts of the studied logics, our initial concepts about care and the use of medications were shifted to some extent, largely due to the intensity of the practice of complex ethnography. By attentively studying practices and relations in two groups, a transformation of our initial hypotheses occurred (Wagner, 2010). We put forward, as Peirano (2004) has argued happens, our own concepts, expectations and choices, at the risk of reshaping them. Ethnography, in this sense, is not only a privileged method for researching care but also a space of powerful theoretical composition regarding care practices.

Notes

1 Those logics are debated in a more detailed way in Engel (2020).
2 One part of this research became part of a wider project on dementia coordinated by Annette Leibing, who had also done fieldwork at the same centre. Janaina Aredes contributed to this chapter with her experience of fieldwork in geriatric care in the city of Belo Horizonte.
3 All names are fictitious.
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4 A controversial medication with limited effect, prescribed for slowing down dementias (Ballenger et al, 2009).
5 A medication prescribed for more advanced stages of dementia, but with no aim of curing the disease.
6 A medication prescribed to deal with sleeplessness and agitation. Although its use is not indicated and the excessive use of the medication by the elderly is even considered a public health problem in Brazil, its consumption remains very common for elderly people with or without dementia.
7 An antidepressant widely used to deal with ‘behavioural’ symptoms of dementia. To learn more about such behaviour-related medications, and to categorize such types of dementia symptoms, see Leibing (2009).
8 The history of extensive prescription of psychotropic drugs for a variety of symptoms in Brazil is widely debated by local social scientists (Maluf, 2018). The frequency of such prescriptions relates to greater patient demand for these drugs, circulation of them among acquaintances and addiction processes.
9 Han (2012) also describes in her work how daily care is entangled in financial relationships and in the creation of debt.

References


