

14 A Life

Between Psychiatric Drugs and Social Abandonment

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VITA

"In my thinking, I see that people forgot me," Catarina said to me as she pedaled an old exercise bicycle while holding a doll. This woman of kind manners and a piercing gaze was in her early thirties; her speech was lightly slurred. I first met Catarina in March 1997 in southern Brazil at an asylum called Vita. I remember asking myself, Where on earth does she think she is going on this bicycle? Vita is the end point. Like many others, Catarina had been left there to die.

Vita, which means "life" in Latin, was founded in 1987 by Zé das Drogas, a former street kid and drug dealer in Porto Alegre, a comparatively well-off city of some two million people. After his conversion to Pentecostalism, Zé had a vision in which the Holy Spirit told him to open an institution in which people like him could find God and regenerate. Zé and his religious friends squatted on private property near the downtown, where they founded a precarious rehabilitation center for drug addicts and alcoholics. Soon Vita's mission expanded. An increasing number of people who had been cut off from social life—the mentally ill and the sick, the unemployed and the homeless—were left at the center by relatives, neighbors, hospitals, and the police. Vita's team then opened an infirmary where the abandoned waited with death.¹

I had traveled through and worked in several poor neighborhoods in the north and south of Brazil (Biehl 2001, 2005, 2006). I thought I knew the country. But nothing I had seen before prepared me for the desolation of Vita when I first visited it in 1995. A local human-rights activist had told me to go there if I really wanted to understand "what people do to people and what it means to be human these days."



14. Vita, 2001. (Courtesy of Torben Eskerod)

Vita was indeed the end station on the road of poverty. Beyond any kind of accountability, most of the two hundred people in Vita's infirmary had no formal identification and lived in abject abandonment and a haunting stillness. For the most part, Vita's staff consisted of residents who had improved their mental well-being enough to administer care to newcomers and to those considered absolutely hopeless. Lacking funds, training, and proper equipment and medication, these volunteers were as ill equipped to deal with Vita's more debilitated residents as the people who ran the establishment. Though Vita's existence was acknowledged by officials and the public at large, it was not the object of any remedial policy.

Some fifty million Brazilians (more than a quarter of the population) live far below the poverty line; twenty-five million people are considered indigent. Although Vita was in many ways a microcosm of such misery, it was distinctive in some respects. A number of its residents came from working and middle-class families and once had been workers with families of their own. Others had previously lived in medical or state institutions, from

which they had been evicted, thrown onto the streets, or sent directly to Vita.

Despite appearing to be a no-man's-land cut adrift, Vita was in fact entangled with several public institutions in its history and maintenance. Porto Alegre contained more than two hundred such institutions, most of which were euphemistically called "geriatric houses." Some 70 percent of them operated as clandestine businesses. These precarious places housed the unwanted in exchange for their welfare pensions; a good number of them also received state funds or philanthropic donations. In Brazil, these zones of social abandonment are symbiotic with changing households and public services: they absorb individuals who have no ties or resources left to sustain themselves, and they actually make residents' regeneration impossible and their dying imminent.

HUMAN-ANIMAL FORMS

Literally left to wither away, many in the infirmary had open wounds filled with maggots and lice. One fifty-year-old man had the maggots drawn from his eyes by an application of Pine Sol and bleach. The inhabitants of the infirmary were treated as nonhuman beings, argued Oscar, the resident-volunteer who guided my initial visits there: "Hospitals think that our patients are animals. Doctors see them as indigents and pretend that there is no cure. The other day we had to rush old Lucas to the emergency room. They cut him open and left surgical materials in him. He died from infections."

The factor that makes these humans-turned-animals unworthy of affection and care is their inability to pay, added Luciano, another volunteer: "The hospital's intervention is to throw the patient away. If they had sentiment, they would do more for them . . . so that there would not be such a waste of souls. Lack of love leaves these people abandoned. If you have money, then you have treatment; if not, you fall into Vita. *O Vita da vida* (the Vita of life)."

Oscar and Luciano used the term *human* to represent something other than the notion of shared corporeality or shared reason that dominates human-rights discourses (Ignatieff 2001). But they did not oppose *human* to *animal* either. Rather than referring to the animal nature of humans, they spoke of the animal nature of medical and social practices and of the values that shape the ways in which supposedly superior human forms treat the abandoned.

"There was no family, we ourselves buried old Lucas. A lone human



15. Vita, 1995. (Courtesy of Torben Eskerod)

being is the saddest thing, worse than being an animal." In emphasizing the "animalization" of people in *Vita*, Oscar and Luciano also conveyed a critical understanding of the relation of the terms *human* and *animal*. The negotiation of these relations, particularly in the medical realm, allows some human-animal forms to be considered inappropriate for life.²

In this essay, I chart Catarina's pathways into *Vita*, and explore the thinking and hope that exist in this zone of social abandonment. I trace the complex network of family, medicine, state, and economy in which Catarina's abandonment and pathology took form. I show how family members use psychiatric diagnostics and treatments to assess human value and to mediate the disposal of persons considered unproductive or unsound. Throughout this narrative, Catarina's life tells a larger story about the integral roles that places like *Vita* play in poor households and city life and about the ways in which novel sociomedical processes affect the course of biology and of dying.³

Following the plot of a single person can help us identify the many juxtaposed contexts and interactions—the “in-betweenness”—through which medical science and social life are empirically worked out. It also illuminates the subjective process by which the abandoned person, against all odds, keeps anticipating another chance at life. How can the anthropological artifact keep the story moving and unfinished?

THE ORIGINS OF PEOPLE

Catarina stood out from the others in Vita, many of whom lay on the ground or crouched in corners, simply because she was in motion. She wanted to communicate. Here is the story she told me when we first met in 1997:

I have a daughter called Ana; she is eight years old. My ex-husband gave her to Urbano, his boss. I am here because I have problems in my legs.

To be able to return home, I must go to a hospital first. It is very complicated for me to get to a hospital, and if I were to go, I would worsen. I will not like it because I am already used to being here.

My brothers and my brother-in-law brought me here. Ademar, Armando . . .

I exercise. . . so that I might walk. No. Now I can no longer leave. I must wait for some time. I consulted a private doctor, two or three times. When it is needed, they also give us medication here. So, one is always dependent. One becomes dependent.

Then many times one does not want to return home. It is not that one does not want to. . . In my thinking, I see that people forgot me.

Later, I asked the volunteers whether they knew anything about Catarina. They knew nothing about her life outside Vita. I repeated some of the names and events Catarina had mentioned, but they said that she spoke nonsense, that she was *louca* (mad). She was a person apparently lacking common sense; her voice was annulled by psychiatric diagnosis.

Catarina’s exercise and her recollections, in the context of Vita’s stillness, stayed in the back of my mind. I was intrigued by the ways her story commingled elements of her previous life, the ways in which medicine had worsened her condition, her present abandonment in Vita, and her desire for a homecoming. I tried to think of her not as a mentally ill person but as an abandoned person who was claiming experience on her own terms. She knew what had made her so, but how was I to verify her account? As Cata-

rina reflected on the events that had foreclosed her life, the degree of unintelligibility in her thinking and voice was not determined solely by her expression: we, the volunteers and the anthropologist, lacked the means to understand them.

As I kept returning to Vita, more and more people said that they wanted to tell me *minha vida* (my life). I was struck by the similarity of the accounts. Most of the residents said that they had no formal identification, and while recalling a home, a family, a childhood, or simply freedom in the streets, they described the specific events that led to their abandonment. As I listened, I was challenged to treat these condensed accounts as evidence of the reality that has been put off limits to the abandoned and of their failed attempts to reenter it. In this sense, these pieces ultimately gave language to the exclusion they embodied. Moreover, for the abandoned themselves, these accounts were spaces in which to rethink their destinies and reframe their desires.

EXPERIMENTAL REGIMES OF HEALTH

"These people in the infirmary represent the putrefaction of the street. They don't exist as a juridical fact. They have AIDS, tuberculosis, all these things that don't exist in statistics," explained Captain Osvaldo. Since 1997, Vita has been administered by Captain Osvaldo, a civilian policeman working for the state of Rio Grande do Sul. Zé das Drogas was evicted from the establishment by a philanthropic coalition called Friends of Vita, headed by Jandir Luchesi, the region's most famous radio-talk-show host and a state representative. During Zé das Drogas's administration, daily life in the rehabilitation area had been structured around worship and Bible studies; now, the emphasis is on personal hygiene, civic values, healthy eating, total abstinence from smoking and drinking, work therapy, and group self-reflection. As for the residents abandoned in the infirmary, the captain was straightforward: "We cannot bring them back to society. As horrible as it is, here one sees a truth."

As I talked to city administrators, public health officers, and human-rights activists, I was able to identify some of the institutional networks through which Vita emerged and has been integrated into local forms of governance, as well as some of the everyday practices that constitute the residents' nonexistence.

With the adoption of Brazil's democratic constitution in 1988, health care had become a public right, and many of the country's discourses and practices of citizenship in the 1990s sought to guarantee this right as the econ-

omy and the state underwent a major restructuring. The activism of mental health workers was exemplary. They worked hard to bring about laws that shaped the progressive closure of psychiatric institutions and their replacement by local networks of community- and family-based psychosocial care. This deinstitutionalization of the mentally ill was pioneered in the state of Rio Grande do Sul (Porto Alegre is its capital), where it was well under way by the early 1990s. In reality, however, the demands and strategies of the mental health movement became entangled in and even facilitated local government's neoliberalizing moves in public health: the mad were literally expelled from overcrowded and inefficient institutions, and the government allocated little new funding for the alternative services that had been proposed.

On the one hand, this local psychiatric reform confirmed the role of Partido dos Trabalhadores (PT), the Worker's Party, as a representative of a novel politics of social inclusion; PT was already in power in the capital. It also occasioned a few exemplary services that treated "citizens burdened by mental suffering" and realized, if all too partially, a socialized form of self-governance. As I later learned, Catarina received treatment in one of these model services in the nearby city of Novo Hamburgo. On the other hand, this psychosocial politics shifted the burden of care from state institutions back to the family and communities, which failed to live up to their idealized representations in the reform movement's discourse. People had to learn new techniques to qualify for services and had to learn to live with the limitations of the new ideologies and institutions. An increasing number of mentally ill people began to live in the streets, along with the other leftovers of the country's unequal and exclusionary social project. Many ended up in places like Vita.

Everyday life in the 1980s and 1990s in that region was marked by high rates of migration and unemployment, the rise of a drug economy in the poorest outlying areas, and generalized violence. As police forces increasingly sought to erase from the city signs of misery, begging, and informal economies, philanthropic institutions took up the role of caregiver, albeit selectively. Simultaneously, families frequently responded to the growing burdens of their new responsibilities for care and narrowing options for employment by redefining their functional scope and value systems. In practice, the experimental mental health plan has also faced the widespread availability of new biochemical treatments. Free drug distribution (including psychopharmaceuticals) is a central component of Brazil's search for a cost-effective universal health-care system. Given the country's neoliberal reforms, drug imports increased substantially in the mid-1990s, and Brazil

is now one of the world's ten largest pharmaceutical markets. The pharmaceuticalization of public health has run parallel with governmental decentralization and the overall demise of clinical infrastructures (Biehl 2006).

In engaging with these new regimes of public health and in allocating their own overstretched and meager resources, families have learned to act as *proxy psychiatrists*. Illness has become the ground on which experimentation and breaks in intimate household relations can occur. Families can dispose of their unwanted and unproductive members, sometimes without sanction, simply for failing to comply with their treatment protocols. This domestic activity of valuing and deciding which lives are worth living runs parallel with gender discrimination, market exploitation, and a managerial-style state that is increasingly distant from the people it governs.

“I WRITE ALL THE ILLNESSES I HAVE NOW”

When I visited Vita in December 1999, Catarina was still there. Now, however, she was seated on a wheelchair and writing.

Catarina looked dazed, and she spoke slowly and with much difficulty. Her health had deteriorated considerably; she insisted that she was suffering from rheumatism. Like most of the other residents, Catarina was taking antidepressants at the whim of the volunteers.

“What are you writing?” I asked.

“This is my dictionary,” she said. “I write so that I don’t forget the words. I write all the illnesses I have now, and the illnesses I had as a child.” Her handwriting was uneven. The words were in block letters, with no cursive writing, and she wrote few verbs or full sentences.

I was amazed by the force of her words:

Divorce
 Dictionary
 Discipline
 Diagnostics
 Marriage for free
 Paid marriage
 Operation
 Reality
 To give an injection
 To get a spasm
 In the body
 A cerebral spasm

“Why do you call it a dictionary?” I asked.



16. Catarina, 2001. (Courtesy of Torben Eskerod)

“Because it does not require anything from me, nothing. If it were mathematics, I would have to find a solution, an answer. Here, there is only one subject matter, from beginning till the end. . . I write it and read it.”

Catarina let me peruse the dictionary.

“I offer you my life.” “In the womb of pain.” “The present meaning.”

Amid the continuous references to consultations, hospitals, and documents, she wrote of “the division of bodies” and of things being “out of justice.” “Who contradicts is convicted.”

“Dead alive, dead outside, alive inside.”

And she wrote expressions of longing:

“Recovery of my lost movements.”

“A cure that finds the soul.”

“With ‘L’ I write Love, with ‘R’ I write Remembrance.”

MICROPOLITICS

I returned to talk to Catarina several times during that visit. She engaged in long recollections of life outside Vita, always adding more details to the story she had told me in our first meeting in 1997. The story thickened as she elaborated on her origin in a rural area and her migration to Novo Hamburgo to work in the city’s shoe factories. She mentioned, in bits and pieces,

PARALITIA.
 PARAZITA.
 PARALIZIA.
 IS PASMÓ. PARALITICO
 K EUMATIA K EUMATICA
 K EUMATICOZI.
 IS PASMÓ ERKEBKAL
 PORTOGUES INGLEZ FRANE
 PORTADA PARMONIA
 POSUEVE ME
 BRONQUITI
 BRONCO PARMONIA
 RECIDA DE PARCO
 RESFRIADO
 PRONICO INFLA
 MAL DE PARCO
 VAKIZES AMINIZIA
 ANEMIA

17. A page of Catarina's dictionary

having more children, fighting with her ex-husband, staying in mental wards. Catarina insisted that her abandonment had a history and a logic:

When my thoughts corresponded with those of my ex-husband and his family everything was fine. But when they disagreed with me, I was mad. It was like a side of me had to be forgotten. The side of wisdom. My brothers want to see production and progress. They wouldn't dialogue and the science of the illness was forgotten. My legs weren't functioning or working well.

The forceful erasure of "a side of me" had prevented Catarina from finding a place in the changing family configuration, I thought.

"Did the doctors ever tell you what you had?" I asked.

"No, they said nothing. . . I am allergic to doctors. Doctors want to be knowledgeable, but they don't know what suffering is. They don't touch you there where it hurts. They only medicate."

Her affections seemed intimately connected to new domestic arrangements: "My brothers brought me to Vita. For some time I lived with my

brothers. . . but I didn't want to take medication when I was there. Why was it only me who had to be medicated?"

"Why," I asked her, "do you think families, neighbors and hospitals send people to Vita?"

"They say that it is better to place us here so that we don't have to be left alone at home, in solitude . . . that there are more people like us here. And all of us together, we form a society, a society of bodies."

Catarina had to think of herself and her history alongside the fact of her absence from the things she remembered: "Maybe my family still remembers me, but they don't miss me."

How to enlarge the possibilities of social intelligibility that Catarina had been left to resolve alone? What are the limits of human thought that she keeps expanding?

In posing these questions, I am not concerned with finding a psychological origin (I do not think one exists) for Catarina's condition or with simply tracking down the discursive templates of her experience. I understand the sense of psychological interiority as ethnological, as the whole of the individual's behavior in relation to her environment and to the measures that define boundaries, be they legal, medical, relational, or affective. Through family complexes and in technical and political domains, as they determine life possibilities and the conditions of representation, human behavior and its paradoxes belong to a certain order of being in the world.

How does one become another person today? What is the price one pays for doing so? How does this change in personal life become part of individual and collective memory? What methodologies can effectively address this agonistic openness of lived experience? How can one incorporate this openness into the analysis of a person's estrangement from reality?

I visited Catarina many times in the following years. I listened intently as she carried her story forward and backward. I also read the volumes of the dictionary she continued to write—a total of twenty-one—and discussed them with her. Taking Catarina's spoken and written words at face value took me on a detective-like journey into the various medical institutions, communities, and households to which she continuously alluded. With her consent, I retrieved her records from psychiatric hospitals and local branches of the universal health-care system. I was also able to locate her family members—her brothers, ex-husband, in-laws, and children—in Novo Hamburgo. Everything she had told me about the familial and medical pathways that led her into Vita matched the information I found in the archives and in the field.

Had I only focused only on Catarina's utterances within Vita, a whole

field of tensions and associations that existed between her family and medical and state institutions, a field that shaped her existence, would have remained invisible. Catarina didn't simply fall through the cracks of these domestic and public systems. Her abandonment was dramatized and realized in the novel interactions and juxtapositions of several social contexts. Scientific assessments of reality (in the form of biological knowledge and psychiatric diagnostics and treatments) were deeply embedded in households and institutions in flux, informing the colloquial thoughts and actions that led to her terminal exclusion. In the story that follows, I want to give you a sense of this powerful, noninstitutionalized ethnographic space in which the family gets rid of its undesirable members.

EX-FAMILY

Catarina was born in 1966 and grew up in a very poor place, in the western region of the Rio Grande do Sul province. In fourth grade, she was taken out of school. Her father abandoned the family, and she became the housekeeper as her youngest siblings aided their mother in agricultural work. In the mid-1980s, two of her brothers migrated and found jobs in the booming shoe industry in Novo Hamburgo. At the age of eighteen, Catarina married Nilson Moraes, and a year later, she gave birth to her son, Anderson.

A semblance. That was the first thing I heard about Catarina as I entered her former house, now occupied by Nilson's sister and her husband and two children.

"When Nilson first brought her photo home," stated Sirlei, "I said, 'Father and mother, look, what a beautiful girl he got for himself.' Everybody agreed."

Today's paralysis was not foreshadowed in the past: "She was then a perfect person, like us," said Sirlei. "She helped with everything." No longer in that family's image, Catarina was now past. She was associated with another disintegrating body: "Her mother also lost the legs and the hands."

Later, Catarina's brothers told me that they, too, were beginning to have problems walking, but they didn't know what the disease was: "It's a mystery." As Ademar, the oldest sibling said, "When we were kids, Catarina was normal." His wife again referred to Catarina's appearance: "She was very normal. I remember the wedding photos." I wondered about this gradation of normality and what elements in one's life or interests determined its application to another family member.

Shady deals, persistent bad harvests, and indebtedness to local vendors



18. Catarina at seventeen, with her future husband. (Courtesy of Torben Eskerod)

forced Nilson and Catarina to sell the land they had inherited to take care of Catarina's ailing mother, and in the mid-1980s, the young couple decided to migrate to Novo Hamburgo and join her brothers in the shoe industry.

Novo Hamburgo had become an El Dorado of sorts, attracting many people in search of work and social mobility. City officials went to the province's western region to recruit a semiliterate and cheap labor force. Statistics show that at the end of the 1980s, the city actually had one of the highest per capita income rates in the state, but at least one-fourth of its growing population lived as squatters. This situation worsened in the early 1990s, when the city experienced an abrupt economic decline and acute impoverishment, mainly because of the country's inability to articulate a more lucrative export policy and because of growing competition from China in the global shoe market.



19. Catarina's wedding party. (Courtesy of Torben Eskerod)

Catarina recalls enjoying her work in the factory. "I had my worker's ID and made my money." Her husband found a job as a security guard in the city hall. Soon the couple had a second child, Alessandra.

Catarina also took care of her mother, who had moved in with the couple. At that time, Catarina began having difficulties walking. "They fired her at the factory, because she began to fall there," said her sister-in-law. At the same time that she lost her value as a worker, she discovered that Nilson was seeing another woman, and her mother passed away. Overwhelmed, at times she left the house and wandered through the city. Her husband deployed his contacts at city hall and made sure that the police went after her: "They had to handcuff her. . . in the emergency ward they gave her shots and she calmed down," he told me. After a few of these episodes, Nilson began confining her in psychiatric units in Porto Alegre.

In the turbulent year of 1992, Catarina gave birth prematurely to her third child, a girl named Ana. Most of her hospitalizations took place between 1992 and 1994, when she and Nilson were no longer living together. "They gave her the best medication," said Nilson. "But she threw it into the toilet and flushed it down. At home, she didn't continue the treatment. She didn't help herself." Nilson now works in a shoe factory and has a new family. Like others, he spoke openly about Catarina. "It's all past," he said. "It is not even in my mind."

BODY AS MEDICATION

Notes on medical treatment and family discussions allow us to retrieve the patient's voice and, more importantly, the narrative of its alteration and the conditions of the patient's supposed intractability. At the Caridade and São Paulo Hospitals, the diagnoses of Catarina's condition varied from "schizophrenia" to "postpartum psychosis," "unspecified psychosis," "mood disorder," and "anorexia and anemia."

In tracing Catarina's passage through these medical institutions, I saw her not as an exception but as a patterned entity. Caught in struggles for deinstitutionalization, lack of public funding, and the proliferation of new classifications and treatments, the local psychiatry didn't account for her particularity or social condition. Thus, she was subjected to the typically uncertain and dangerous mental health treatment reserved for the urban working poor. Clinicians applied medical technologies blindly, with little calibration to her distinct condition. Like many patients, Catarina was assumed to be aggressive and thus was overly sedated so that the institution could continue to function without providing adequate care.⁴

Although Catarina's diagnosis softened over the years (mimicking psychiatric trends), she continued to be overmedicated with powerful antipsychotics and all kinds of drugs to treat neurological side effects. On several occasions, nurses reported hypotension, a clear indicator of drug overdose. For Catarina, as for others, treatment began with a drug surplus and was then scaled down, or not, through trial and error. As I read her files, I could not separate the symptoms of the psychiatric illness from the effects of the medication, and I was struck that doctors did not bother to differentiate between the two in Catarina.

To say that this approach is "just malpractice," as a local psychiatrist says, misses the productive quality of this unregulated medical automatism and experimentalism: *Pharmaceuticals are literally the body that is being treated*. And the process of overmedicating Catarina caused many of the symptoms that she called "rheumatism." As doctors remained fixated on her supposed hallucinations, the etiology of her walking difficulties, which nurses actually reported, remained medically unaddressed. The medical records also show that her husband and family were difficult to contact, that they left wrong telephone numbers and addresses, and that on several occasions, they left Catarina in the hospital beyond her designated stay.

Catarina's dictionary is filled with references to deficient movement, pain in her arms and legs, and muscular contractions. In writing, as in speech, Catarina refers to her condition, by and large, as "rheumatism." I followed

the word *rheumatism* as it appeared throughout the dictionary, paying close attention to the words and expressions clustered around it.

At times, Catarina's writings relate her growing paralysis to a kind of biological and familial marker, alluding to a certain "blood type becoming a physical deficiency," "a cerebral forgetfulness," and an "expired brain and aged cranium" that "impede change." Most of the time, however, Catarina writes of the man-made character of her bodily affections. In the following inscription, for example, she depicts rheumatism as a mangling of the threads that people tinker with:

People think that they have the right to put their hands
 In the mangled threads and to mess with it
 Rheumatism
 They use my name for good and for evil
 They use it because of the rheumatism

Her rheumatism ties various life threads together. It is an untidy knot, a real matter that makes social exchange possible. It gives the body its stature and is the conduit of a morality. Catarina's bodily affection, not her name, is exchanged in that world: "What I was in the past does not matter."

In another fragment, she writes:

Acute spasm
 Secret spasm
 Rheumatic woman
 The word of the rheumatic is of no value.

In my view, the "secret" of Catarina's condition stemmed from an unknown biology and the unconsidered experience of how people had defined it over time. We must consider side by side the acute pain that Catarina described and the authoritative story she became in medicine and in common sense—as being mad and ultimately having no value. The antipsychotic drugs Haldol (haloperidol) and Neozine (levomepromazine) are also words in Catarina's dictionary. In a fragment, she defiantly writes that her pain reveals the experimental ways of science:

The dance of science
 Pain broadcasts sick science, the sick study
 Brain, illness
 Buscopan, Haldol, Neozine
 Invoked spirit

The goods of psychiatric science, such as Haldol and Neozine, have become as ordinary as Buscopan (an over-the-counter antispasmodic medica-

tion) and have become a part of familial practices. As Catarina's experience shows, the use of such drugs produces mental and physical effects apart from those related to her illness. These pharmaceutical goods—working, at times, like rituals—realize an imaginary spirit, rather than the material truth they supposedly stand for: medical commodities become supposed subjects. A moneymaking science plays a role in Catarina's afflictions. As transmitters of this science, her symptoms are typical.

"I need to change my blood with a tonic. Medication from the pharmacy costs money. To live is expensive," she wrote.

"Did Catarina tell you what happened in the hospital?" I asked her ex-husband.

"No, she didn't remember."

"MY DESIRE IS OF NO VALUE"

A complex plot had developed. After talking to all parties, I understood that, given certain physical signs, Catarina's husband, her brothers and their respective families believed that she would become an invalid as her mother had been. They had no interest in being part of that genetic script. Catarina's "defective" body then became a kind of battlefield in which decisions were made within local family/neighborhood/medical networks about her sanity and ultimately about whether "she could or not behave like a human being," as her mother-in-law said. With Catarina depersonalized and over-medicated, something stuck to her skin—the life determinants she could no longer shed.

As Catarina's situation worsened, Nilson found another woman, with whom he had a child, and had a judge grant him legal separation from Catarina. Catarina never signed the divorce papers herself. Her ex-husband also signed over his youngest daughter, Ana, to his boss in the city hall, but he insists that Catarina "gave her away." Nilson and his mother each kept one of Catarina's other two children, who still help in their respective domestic economies. At the height of Catarina's despair, her brother-in-law made her accept a deal in which he took her house and moved her into his shack, deeper into the slum.

Given that Catarina had been given away to Nilson and that the young couple squandered the family's land, Catarina's brothers felt no obligation to her. This attitude expressed the economic and gendered fabric of their moral thinking, beyond the domain of the blood tie. In more than one way, Catarina was repeating the script of her mother's illness experience: For

both women, the development of the disease was entangled with spousal separation, abandonment, and predatory claims to available goods.

To Catarina's complete devastation, at the end of December 1994, her shack burned down and she was hospitalized again. This time, a Dr. Viola wrote, "I am against admission; patient should have a neurological evaluation." Nevertheless, Catarina was locked up and treated, as I learned, with haphazardly combined antipsychotic medications. On discharge, she wandered from one relative's house to another. Backed by a private psychiatrist, family members and neighbors experimented with many drugs and dosages.

"Bottom line, the ethics the family installs around mental suffering guarantees their own physical existence," I was told by Simone Laux, the director of the Novo Hamburgo psychosocial service where Catarina went before and between hospitalizations. One of her colleagues agreed that "the family quite often replaces a state that does not care." The family is thus a state within the state. In this bureaucratically and relationally sanctioned register of social death, the human, the mental, and the chemical are complicit. Finally, in 1996, after hearing about Vita from a Pentecostal pastor who knew of the place from a radio program, the brothers left her there.

In this dire context and in the face of disease, how does one speak of the "evil" that is done and the good one must do? For Ademar and other family members, the question was a rhetorical one to which the unspoken answer was "nothing": "It's tough, but what to do?" In the end, Catarina represented a failed medication regime that, paradoxically, allowed the lives, sentiments, and values of others to continue in a constantly changing social field marked by economic pressure and violence.

I do not mean to suggest that mental disorders are basically a matter of social construction, but rather that such disorders take form at the most personal juncture between the subject, her biology, and the technical and intersubjective recoding of "normal" ways of being in local worlds. Hence, mental disorders also implicate people who claim to represent common sense and reason, and these people have the responsibility to address their embroilment in the unfolding of disorders.

Catarina cries and wants to leave
 Desire
 Watered, prayed, wept
 Tearful feeling, fearful, diabolic, betrayed
 My desire is of no value
 Desire is pharmaceutical
 It is not good for the circus

We can now more fully understand what Catarina meant when she said that she was writing a dictionary so as “not to forget the words, all the illness I had as a child and that I have now.” The illnesses she now experienced were the outcome of events and practices that altered the person she had learned to become.

The drug Akineton, which aims to control the side effects of antipsychotics, was embedded in the new name Catarina gave herself in the dictionary: “CATKINE.”

THE WORK OF TIME

I was able to get the genetics service of the Hospital das Clínicas, one of the ten best in the country, to see Catarina. Fourteen years after Catarina entered the maddening psychiatric world, molecular testing revealed that she suffered from the genetic disorder Machado-Joseph Disease, which causes degeneration of the central nervous system (Coutinho 1996; Jardim et al. 2001b). The disorder is inherited as an autosomal dominant disease (Jardim et al. 2001a) and was first reported in North American families of Portuguese-Azorean ancestry (Boutté 1990; Sequeiros 1996). The disease is characterized by a progressive cerebellar ataxia affecting gait, limb movements, speech articulation, and deglutition. Catarina’s brothers had the same diagnostics and were able to use it to obtain disability benefits.

I was happy to hear that the geneticists who saw Catarina reported that “she knew of her condition, past and present, and presented no pathology.” Dr. Laura Jardim was adamant that “there is no mental illness, psychosis or dementia linked to this genetic disorder. In Machado-Joseph your intelligence will be preserved, clean, and crystalline.” Of course, biopsychiatrists could argue that Catarina was affected by two concomitant biological processes, but for me, the discovery of Machado-Joseph was a landmark in its overwhelming disqualification of her as mad and its ability to shed light on how her condition had evolved.

While reviewing the records of the one hundred families under the care of Dr. Jardim’s team, I found that spousal abandonment and early onset of the disease were quite common among women, just as Catarina, her mother, her younger aunt, and a cousin had experienced. Affective, relational, and economic arrangements take shape around the visible carriers of the disease, and these gendered practices ultimately affect the course of dying. I also learned that after disease onset, Machado-Joseph patients survive on average fifteen to twenty years, most dying from pneumonia in wheelchairs or bedridden. Scientists have firmly established that the graver the gene mu-

tation, the more it anticipates disease. And though the gravity of the gene mutation can account for 60 percent of the probability of earlier onset, the unknown 40 percent remains. Among siblings, Dr. Jardim told me, "the age of onset is almost always the same." How then can one explain Catarina's early onset, in her late teens, and her brothers' onset in their mid- to late twenties?

The various sociocultural and medical processes in which Catarina's biology resided, I thought, pointed to the materiality and morality of this "unknown 40 percent"—in other words: the social science of the biological mutation. To this notion, Dr. Jardim responded, "At the peak of her suffering, they were dismembering her. . . this dying flesh is all that remained." Rather than being the residue of obscure and undeveloped times, Catarina's condition was part of a regularity, forged in all the public spaces and hazy interactions in which a rapidly changing country, family, and medicine met.

The ethnography of Vita makes it painfully clear that there are places in the present, even in a state founded on the premise of inviolable human rights, where these rights no longer exist, where the living subjects of marginal institutions are constituted as something other, beings between life and death. Such places demonstrate that notions of universal human rights are socially and materially conditioned by medical and economic imperatives. Vita also reveals the extent to which a certain kind of human-rights discourse—the sort that generates "model programs" in restructuring states and economies—in practice works by a logic of exclusions; and it confirms that public death remains at the center of various social structures, animating and legitimating charity, political actors, medical ethics, and various domestic strategies.

In her thinking and writing, Catarina reworks this literality that creates her sense of exclusion. She discovers her subjectivity in relation to this tinkering and by making herself heard in a place where silence is the rule.

"I am not a pharmacist," Catarina once told me. "I cannot say which medication heals an illness, I cannot say the name of the pharmakon, but the name of my illness I know . . . How to say it?"

Silence.

She then said: "Mine is an illness of time."

"What do you mean?"

"Time has no cure."

NOTES

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1. Scholars of contemporary Brazil argue that the dramatic rise in urban violence and the partial privatization of security and health care have deepened divisions between the marketable and the socially excluded (Caldeira 2000; Escorel 1999; Fonseca 2002; Goldstein 2003; Hecht 1998; Ribeiro 2000). All the while, newly mobilized patient groups continue to demand that the state fulfill its biopolitical obligations (Biehl 2006). As economic indebtedness, ever present, transforms communities and revives paternalistic politics (Raffles 2002), larger segments of the population articulate citizenship in the sphere of consumer culture (Edmonds 2002; O'Dougherty 2002). Overburdened families are suffused with the materials, patterns, and paradoxes of these processes, which they by and large, must negotiate on their own.

See Nancy Scheper-Hughes's (2001) study of how shifting domestic economies affected family ties and mental illness in rural Ireland in the 1970s. See Luiz Fernando Dias Duarte (1986) for an analysis of "nervousness" among the urban poor in Brazil.

For a critical review of current social policies developed by the Brazilian state, see Fiori 2001 and Lamounier and Figueiredo 2002. Also see Hoffman and Centeno's (2003) review of persistent inequality in Latin America.

2. In the early 1990s, anthropologists began to follow the production of new biocientific knowledge and the making of biotechnologies, inquiring into their multiple deployments and their interactions with old and new forms of power relations and ethical models (Rabinow 1999; Rapp 1999; Strathern 1992). Paul Rabinow (1996), for example, notes a dissolution of the traditional social domain and the emergence of new forms of identity and moral reasoning in light of the technical possibility of literally remodeling life (a phenomenon he calls "biosociality"). The recent work of anthropologists Veena Das (1997, 2000), Arthur Kleinman (1999), Allan Young (1995), Nancy Scheper-Hughes (2000), Margaret Lock (2002), Lawrence Cohen (1998), and Adriana Petryna (2002), among others, shows how medical and technical interventions affect—sometimes for better, sometimes for worse—the etiology, experience, and course of disease. The appearance and distribution of disorders such as drug-resistant tuberculosis and AIDS also correlate closely with poverty and social and technological inequality. These disorders are "pathologies of power" (Farmer 2003) mediated by biological, social, and technical and political-economic mechanisms. Concrete biological phenomena are thus intertwined with environmental conditions that are part of a larger context. On disability and citizenship, see Das and Adlakha (2001).

3. As George Marcus points out, "Life histories reveal juxtapositions of social contexts through a succession of narrated individual experiences that may be obscured in the structural study of processes as such" (1998: 94; see also Fischer 1991,

2003; Mattingly 1998). See Behar 1993; Crapanzano 1980; Das 2000; Desjarlais 2003; Goldstein 2003; Pandolfo 1998; Panourgíá 1995; and Shostak 1981.

Ochs and Capps (1996) review the expansive literature relating notions of the self to practices of narration, and Good (1994), Desjarlais (1994), and Chatterji (1998) discuss how far such ideas can go in interpreting the lives and words of the mentally ill; Scheper-Hughes and Lock (1987) expand on the “mindful body.” On embodiment, see Csordas 1994, and on care and belonging, see Borneman 2001.

4. In dealing with psychosis, Jacques Lacan (1977: 216) urged psychiatrists and psychoanalysts to halt diagnosis and question their own trust in an order of reality; he also let patients define their own terms. See also Corin 1998; Corin and Padmavati 2003.

Ian Hacking has identified scientific and technical dynamics that mediate among processes by which “people are made up” (1990: 3; see also Hacking 1999).

For the broader literature on antipsychiatry debates and movements, see Laing 1967 and Scheper-Hughes and Lovell 1987. For interpretations of psychiatry and psychology in the United States and Western Europe, see Goffman 1961, Lührman 2000, and Rose 1998, 2001; and for interpretations in Brazil, see Costa 1976. On new taxonomies of mental illness and psychopharmaceuticals and their clinical and politicoeconomic imbrications, see Young 1995, Cohen 1998, and Healy 1999. On the braiding of imaging technologies with new regimes of personhood, see Dumit 2004.

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