Unfinished

The Anthropology of Becoming

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Hereafter

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It was eerie to return to southern Brazil in August 2005 knowing that Catarina would not be there. Catarina had passed away in September 2003, a few weeks after I had last seen her. I was shocked by the news, for when I last talked to Catarina, her physical condition seemed to be improving. Oscar, Vita's chief caretaker, had kept his promise and made sure that she was regularly taken to the genetic medicine clinic for medical checkups and speech therapy. She was excited when I told her that, with the medical report in hand, we would begin procedures to get her a disability pension. In spite of much pain in her joints, Catarina kept writing, and she wanted to make sure that I could read her writing—which I could. Oscar participated in that last conversation. All he wanted, he said, was "to build my house" in the village around Vita. A package of cement and sets of bricks made him the happiest of men.

Catarina wanted to get out of her wheelchair, she said, and she began to weep: "I need to go to Novo Hamburgo, to get my documents. Another person cannot get them for me. . . . I want to go home."

What stayed in my mind as I left that day was Oscar saying: "They don't have the right to be persons." And then Catarina's comment: "I am part of the origins, not just of language, but of people. . . . I represent the origins of the person."

Two weeks later, Oscar called to tell me of her passing. The women in the dorm told Oscar that during the night, Catarina had called for her mother many times and then fallen silent. The next morning, she was found dead.

Laura Jardim, the doctor who was overseeing Catarina's treatment, was positive that she could not have died from complications from Machado-Joseph Disease and requested an autopsy. The autopsy revealed that Catarina died as a result of intestinal bleeding.

The wear and tear of Vita, the silent work of killing, I still think.

When I made it back to southern Brazil in 2005, I wanted to get a headstone for Catarina's grave, and I decided to visit Vera and Marino, the adoptive parents of her youngest daughter, Ana. The couple had helped to organize Catarina's burial in Novo Hamburgo's public cemetery. The family, as Oscar had told me, "at least took the dead body home." Ana was helping at the family's restaurant when I arrived. At thirteen years of age, she had a face and gaze that were indeed extensions of Catarina's.

Vera did most of the talking. She lambasted every single member of Catarina's family, saying how "fake" they had all behaved during the funeral. Only Nilson, Catarina's ex-husband, had shown "respect," by offering to help defray some of the funeral's costs.

It was striking how Catarina's story continued to shift in the years following her death. In people's recollections, she was no longer seen as "the mad woman." Both Vera and the relatives I saw later that week now spoke of Catarina as having "suffered a lot."

As true as this was, such renderings left unaddressed the everyday practices that had compounded her intractability—most obviously, the cold detachment that accompanied care conceived solely as pharmaceutical intervention rather than as a relational practice too. Indeed, the plot of a life story is never securely in the possession of its subject. It is part of the ongoing moral work of those who live on.

One morning in August 2005, Vera and I drove to the cemetery. I used to visit this place as a child with Vó Minda, my maternal grandmother. We would make hour-long walks uphill to wash the white pebbles adorning her son's grave and to leave flowers from our backyard. Nowadays the cemetery occupies the whole hill, overlooking a city that has also changed beyond recognition. The cemetery has now become a site of pillage. Anything on the graves that might have had some monetary value, from the metallic letters spelling out the names of the deceased to religious icons, had been looted. So much for the value of memory, I told Vera. She shrugged, not knowing how to respond. I was not sure what I intended either, beyond giving voice to mourning.

The story of a life is always also the story of a death. And it is up to us to project the story into the future, helping shape its afterlife. Catarina had

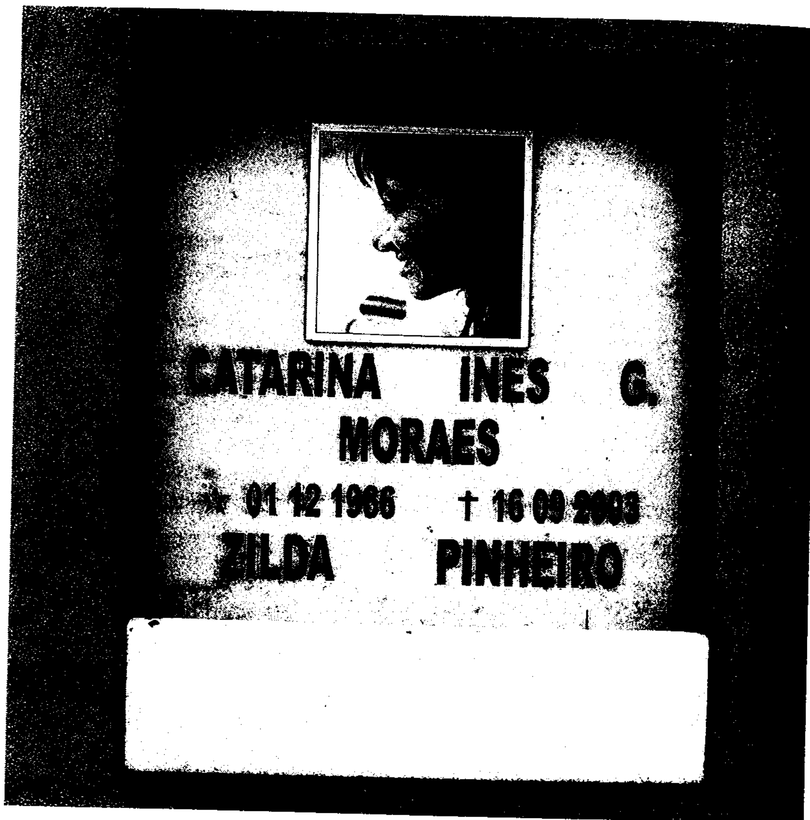

FIGURE 11.1 Catarina's tombstone, Novo Hamburgo, 2011

been buried in a crypt together with her mother's remains. I made sure that the crypt was fully paid for, so that in the future their remains would not be thrown into the mass grave at the edge of the cemetery. And Vera was going to oversee the making of a marble headstone with Catarina's name engraved on it, along with a photo taken by my longtime collaborator and friend Torben Eskerod: a beautiful image of Catarina smiling that no one could take away.

TELL MY STORY

That winter I also returned to Vita.

Inside the infirmary, things had only gotten worse. The bedridden were not even brought into the sun's meager warmth. I asked for Iraci, Catarina's good friend. I found him crouched in bed. He said he was so happy to see me and began to cry silently. So did I. Yes, Catarina had died "all of a sudden," as had

India, the young woman Iraci called wife and had so dearly looked after. He then asked this simple and piercing question, which still haunts me: "Did you bring the tape recorder?"

I had not. Now it was his time to tell the story.

Iraci—much like Catarina—called on the ethnographer to help give shape to his own life story. In the recent lecture "Tell My Story," the literary scholar Stephen Greenblatt follows his "compulsive fascination with the power and pleasure of stories" to interrogate their stakes and possibilities.[1] Through a discussion of the Judeo-Christian origin myth, he explores our need for life stories: while Genesis glosses the lives of Adam and Eve in a few words and gives just sparing details, denoting only the barest trajectory of the fall and what came after, Greenblatt sees in the Apocrypha a response to our deep need for a story. If Genesis imagined the origin of life, the apocryphal texts imagine the origin of the story of *a* life: "Genesis tells us what it would have been like to be human, but not have human life stories." The Apocrypha, he tells us, "grope to supply these details."

Also drawing on Shakespeare's *King Lear* and attentive to the relationships between body, history, storytelling, and death, Greenblatt is interested in human longevity beyond reproductive life—"least relevant to the biological processes of life history." "This consciousness," he states, "has no claim on the attention of evolutionary biologists. It is, like the nonreproductive bodies of the very old, a kind of meaningless leftover." He goes on: "But for Shakespeare, and for literature, the leftover is the thing itself."

It is precisely here that the human story resides, as does the impulse that propels the Apocryphal texts to ask not only if Adam and Eve lived, but how. Where for biology, it is an "epiphenomenon" (at best, a ruse; at worst, an irrelevance), in literature, Greenblatt asserts, "life story is the platform for human experience." Beyond productive and reproductive life, he tells us, what matters most to Shakespeare is "what lies just ahead"—the rage, grief, madness, and fantasies of a redemption that will never come—the very stuff of stories.

How, then, does this stuff of our stories continue, drawing our subjects and ourselves into an ethnographic open system?

"YOU WILL REMEMBER MY CASE"

In November 2014, I received an e-mail message from someone I did not immediately recall: Andrea de Lima.

The subject line read: "Mr. João Guilherme [which is how I am addressed in Brazil]—MJD [which stands for Machado-Joseph Disease]—family

case—Vita [where I met Catarina]." There was much more at work in that composite subject than I could immediately apprehend.

"Good morning, Mr. João Guilherme, she wrote, in a youthful, neighborly and respectful manner. "It is a great pleasure to be sending you this email."

The message seemed affectively important to her. "I got your contact information from Mr. Magnus at Vita, here in the state of Rio Grande do Sul, Brazil," she informed me. She had gone out of her way and into Vita, searching to establish contact with the anthropologist whom Catarina had known.

"My name is Andrea," she continued.

By then I knew who was writing. In *Vita,* I had named her Ana.[2]

A puzzling statement followed: "I'm looking for you for the following... you will remember my case."

How could I not? I felt deeply implicated. The character had acquired a Shakespearean ghostly tone, like in Hamlet: "Remember me."

Yet this was not just a call for personal recognition. The memory she invoked was that of her "case"—a broader story she was a part of. Andrea was looking for the ethnographer of Vita. She trusted that he knew of her particular situation and that she was not just an anonymous floating sample of something occurring in the world: "I am the daughter of Catarina Inês Gomes who spent years living in Vita with Machado-Joseph Disease and you accompanied her case."

My work with Catarina had unleashed something into the world, something that surfaced all these years later in Andrea. While Catarina had sought to detach herself from the logics that produced her abandonment, her daughter was, in a sense, trying to attach herself to something—to enter into the entanglements that brought kin, biology, and anthropologist together. Now it was Andrea who was trying to reassemble the dismembered family.

In her email, she wrote: "I was adopted by Vera. So my last name was changed. My siblings stayed with the blood family."

Catarina once told me that she had never signed the adoption papers. Indeed, given her supposed madness and recurrent psychiatric hospitalizations, she never got her day in court to contest her husband's decision to sign away custody of Andrea.

Twice in this initial message, Andrea invoked the genre of the case: her own and her mother's. As the literary theorist Lauren Berlant notes, cases—legal, medical, or psychological—are defined by judgment. Linking the singular to the general, they express "a relation of expertise to a desire for shared knowledge."[3] But is the case only or always about judgment? And how does anthropological work—and the systems it engenders over time and space—enter into proximity with such cases?

Andrea knew that those who had seen her mother as unproductive, unfit, and mad had closed Catarina's life off. Yet by exploring how Catarina became a case—of psychosis, expert knowledge, and abandonment—anthropological work had made room for thinking reality and human figures otherwise. Ethnography brings crossroads (places where other choices might be made, other paths taken) out of the dustbin of history or the shadow of encased norms and deterministic analytics—the "leftovers," in Greenblatt's sense, that make up a life. Through ethnography, there is a refusal of encasing and its confines, including the values, systems, experts, and institutions through which the case is constituted. Andrea was curious about how her mother managed to survive in Vita and what her writing meant to her.

According to Berlant, cases can also trouble norms and create openings: "The case reveals itself not fundamentally as a form, but as an event that takes shape."[4] By breaking the case open, ethnography creates a spacetime separate from the event, which is the very spacetime that Andrea entered. In this way, a case "raises questions of precedent and futurity, of canons of contextualization, of narrative elucidation," writes Berlant, and "a personal or collective sensorium shifts."[5]

While cases can be—and indeed often are—domains of normative power and expert judgment, they are also a means of moving into the unknown. They offer not so much judgment as an invitation, entry point, or adjacency, or the becoming of a life story, which is an open system that the ethnographer in this case has become a part of. Ethnography thus makes the case "an opening within realism, suggesting where it might travel."[6]

In her e-mail Andrea told me, "I want the genetic test so that I can know whether I am negative or positive" for Machado-Joseph Disease.

Part of a dismembered family, Andrea knows that she also belongs to a biological system that exercises its own kind of agency. The knowledge she seeks is life-altering. If she tests positive, she will be diseased, so to speak, and left

without a known treatment. I did not know how to take what I was reading or how to respond to her search, and I was thrown back to the core tension of my fieldwork with Catarina: how to sustain a sense of hope, as mortality hovers beneath the surface.

ONWARD

"I am very grateful that you attended to my mother and also to Adriano. For I know that some years ago, you helped him."

Andrea was right. A couple of years earlier, I had returned to southern Brazil to work on a visual documentary of the now-ubiquitous practice of litigation against the state for access to treatment. Torben had joined me in the field, and at that time we met with Laura Jardim, the doctor who had seen Catarina before her death, to discuss the plight of patients who are filing lawsuits for access to new and high-cost genetic therapies. At the end of the meeting, Laura mentioned that Catarina's son, Adriano, had recently visited her clinic and received the same diagnosis of Machado-Joseph Disease as his mother had had. He had been invited to enroll in the first clinical trial for a treatment that the genetics team hoped would slow the progression of the disease.

Fieldwork sets often surprising and unforeseeable processes in motion, changing something in the life course of all involved. My work with Catarina made me a part of what I have come to think of as an ethnographic open system. Between fieldwork's past and future, I was linked to both Catarina and her offspring. In contrast to the subjects of statistical studies and the figures of philosophy or social theory, our ethnographic subjects have a future, and we become a part of it in unexpected ways. Their stories become a part of the stories we tell, and we, too, become a part of their life stories.

I found Adriano, his wife, and their two children living in the poorest outskirts of the city of Novo Hamburgo, not far from where I grew up. The meeting with Adriano and his family taught me much about the dark underside of Brazil's ailing public health-care system. Unable to continue his work in the local steel factory, Adriano was getting by on a disability stipend that he had to reapply for every three months. His son had severe learning disabilities. After a year of trying, the family was still waiting for an appointment with a neurologist. His daughter was tiny, apparently undernourished; she had an umbilical hernia, and they were also having trouble making the appointment for her operation.

Living in the brutal stasis of poverty, Adriano and his wife seemed resigned to waiting. Their situation reveals the broad reality of public health among Brazil's poor: unless they learn to make themselves visible, demand fulfillment of their rights, and make the system care, they are left to live with their conditions and eventually die on their own.

Despite their difficult circumstances, there was something of Brazilian consumer society in Adriano's remote shack. The children sat on a sofa playing video games. Adriano dreamed of building a house with a yard for the kids to play in, he said, and he had managed to acquire an old Volkswagen Beetle—even though he did not have a driver's license. These possessions and desires helped him maintain a sense of worldliness and worthiness, I thought, as he now fought to escape Catarina's destiny—Vita.

"Onward," he said.

RETURN TO VITA

Together with Torben, I returned to Vita once more in August 2011.

"Welcome back," said Magnus, the soft-spoken senior citizen who had been in charge of Vita's daily operations for more than a decade. "Make yourself at home."

Vita has changed along with Brazil. It is now as much a makeshift institution of care as it is a zone of social abandonment. There is a nursing wing for the elderly and disabled, separate from the infirmary where I first met Catarina, and a social worker on staff is responsible for triage. Only people with retirement pensions or disability benefits and a certain level of well-being are accepted.

I interrupted Magnus to ask if two men seated in wheelchairs next to each other were Vaquinha (literally, "little cow") and Caminhãozinho (literally, "little truck"), the names I had come to know them by over the years. They were severely mentally impaired, and no one knew anything about their lives before Vita. I had actually written something about the pedagogical role the abandoned person/animal/object played for inmates who, by informally adopting men like Vaquinha and Caminhãozinho, were trying to rehabilitate and regenerate themselves as citizens.

In a striking turn of events and in line with Brazil's new rule of law, the abandoned had formally become citizens, I learned. During an audit by the Public Ministry, officials had demanded that the legal situation of everyone living at Vita be regularized. Vaquinha is now João Paulo Nestore Soares, and Caminhãozinho

is Samuel Lopes. They had names and dates of birth invented for them and were issued social security and identity cards. With these cards in hand, João Paulo and Samuel were now entitled to disability benefits, which are channeled to the institution. Yes, formal channels of social inclusion are taking root even in places like Vita, but of course citizenship and care remain a money-making matter.

We found a bedridden man in a small room with an empty chair and a television. Caregivers refer to him as "uma antiguidade"—"an antique" or "a person of those earlier times"—because he has survived in Vita since its beginnings in the mid-1980s. Motionless, he was purged of specificity, a sort of human mineral with no human touch or voice to awaken flight, a person connected to nothing and no one. I know that no emotion or image within me can represent this life story, which, like most, will remain unknown.

A resident named Vilma beckoned us. She was unable to walk on her own. Three months earlier, Vilma had been left by her husband at Vita with a few clothes, a record of psychiatric prescriptions, and the prospect of a disability pension to be collected by Vita. Vita's administrators were adamant that, by and large, people who were left at Vita required full-time care and thus prevented another family member from working. Simply put, in today's economy, a family unburdened of day-to-day caregiving responsibilities can generate much more money.

It was uncanny how much Vilma's story mirrored Catarina's. As I listened to her, I was thrown back to the beginnings of Vita (both the place and the book), to knots of intractability, a reality that kills, and the desire to bring this reality to justice and tell it all.

But how?

HOW LITERAL THE VIRTUAL FIGURE IS

A few days later, we were back.

"I think that's Lili," I told Torben. "She was Catarina's roommate; you photographed her in 2001."

With a shaved head and aged beyond her years, yes, it was Lili, seated on a bench next to a man with a large build.

"Hi, Lili."

"Hi."

"Do you remember me?"

"I cannot remember you, sir."

"We talked many times, when Catarina was alive. I did not wear glasses then," I said, and I took my glasses off.

"Ah . . . yes, now I recall, *the times of Catarina.*"

"This is Torben, a friend of mine. He also photographed you. You told us about your family."

"Was it you who took me to the bank to get that money?"

"No," I said. Most likely it had been a Vita administrator taking her to collect her pension.

Lili then introduced us to Pedro: "I am married to this guy now. It is good to have someone, and they don't let us sleep together . . ."

Lili added that she had been "ill . . . of the nerves . . . I don't recall things . . . I had not recalled you."

"Do you take medication?"

"Yes. I am talking the red pill, the blue one, and the little white one, every day."

Torben asked to photograph the couple.

"But I have no money to pay for it," Lili said, to Pedro's laughter.

During the photo shoot, Lili asked me: "Are you married?"

"Yes. My wife's name is Adriana. And we have a son called Andre."

"I also have a son. There he is." She pointed to a volunteer who was helping an elderly man to his wheelchair.

I tried to shift the conversation to what I thought was real and asked: "Do you miss your son?"

"Now he is living nearby and he often comes to visit. My daughter-in-law also comes and brings me sweets."

I recalled that Lili had always spoken about going to church and quoted passages from the Bible. I asked her whether there were still worship services in Vita.

"No, they don't let us go to church now. . . . I used to go to the Assembly of God and to the God Is Love Church. I went to both."

"But you pray . . ."

"Yes, I pray. I think of God, but I never saw God."

I was puzzled. Lili meant it literally: "I only saw the Son of God on a crucifix. It was in a pamphlet they gave me at the hospital."

With a little trust restored between us, Lili spoke of everyday life in Vita: "I don't even know how long I have been here. Sometimes life here is good, sometimes it is bad." She lamented the cruel treatment inflicted by volunteers, with the exception of her "son."

She was referring to Jorge, the infirmary's head caregiver, who joined us. He had not overheard our conversation and revealed how literal the virtual figure is for the abandoned: "I am the one who is always joking with her. I tell her that I am her son."

And so, through and beyond the times of Catarina, the writing of Vita continues, amid cruelly optimistic yet sustaining attachments. People keep claiming the social roles and connections that have been denied to them, attaching themselves to the potentiality of words to create ties, allowing at least a minimal sense of personhood and human value.

UNTHOUGHT

"Please confirm that you received this message," Andrea pleaded in her e-mail to me. "You are very important in my history and in my family. I hope you will remember me or my family that you became a part of."

Besides family, biology, history and work ("I'm sending this e-mail from work," she said in a postscript), Andrea was also part of an ethnographic open system constituted by the circuits of fieldwork and the work of time.

"Thank you," Andrea concluded the message.

We began a conversation over e-mail and Skype. Andrea had finished high school, and when she turned eighteen, she said, it was time to leave the home of her adoptive parents: "Vera and Marino gave me a home and education, and I always had everything I needed. I cannot complain. But it was never an affectionate relationship."

Andrea was working as a computing and customer service assistant at a transportation company in Novo Hamburgo, and for the past three years, she had been living with her boyfriend, Anderson, and his working-class family. "Not a single day goes by that I don't miss my mother," she told me.

She only recalled having seen Catarina once. Her adoptive parents took her to Vita and "I did not know what to say. All that human misery. I regret so much not asking her any questions. I was afraid." She was ten at the time. Vera had told me that they had actually taken Andrea to Vita "for her to see what will happen to her if she does not start behaving."

Through the ethnographic complex, Andrea sought an identification with Catarina. She asked whether I could reach out to the same doctor who had tested and treated her mother and her brother, Adriano—which I did, although I was ambivalent about doing so. If it were me, I would not want to know if I had such a disease. I worried about what would happen to her current life, which seemed well-organized and stable, if she were found to have the genetic mutation for Machado-Joseph Disease. Yet Andrea was determined to know and went through a long process of evaluation and counseling. It was as if the lethal genetic knowledge would confirm that she was in fact the daughter of the mother who, encased in madness and abandonment, she never had.

A year later, in November 2015, Andrea e-mailed me again and asked if we could talk.

I thought she wanted to tell me the outcome of the genetic test. But that was not it. She had not yet been called to get the results. I knew from my geneticist colleagues that about half the people who get tested decide not to see their results, and I told her that this option was available to her.

"My sister and I found each other on Facebook," she told me.

That was the story Andrea wanted to tell. She was over the moon with happiness. The last time Andrea had seen her oldest sister, Adriana (who had been raised, together with Adriano, by a paternal grandmother), was at Catarina's funeral.

"I saw her message on a Sunday morning when I woke up," she told me. "Can you imagine? I cried a lot."

This is a snapshot of their digital encounter. The English translation of what they said is: "Hi Andrea, all good?" "I think I found the person I sought my entire life, the person I loved my entire life." "You are my little sister, right?"

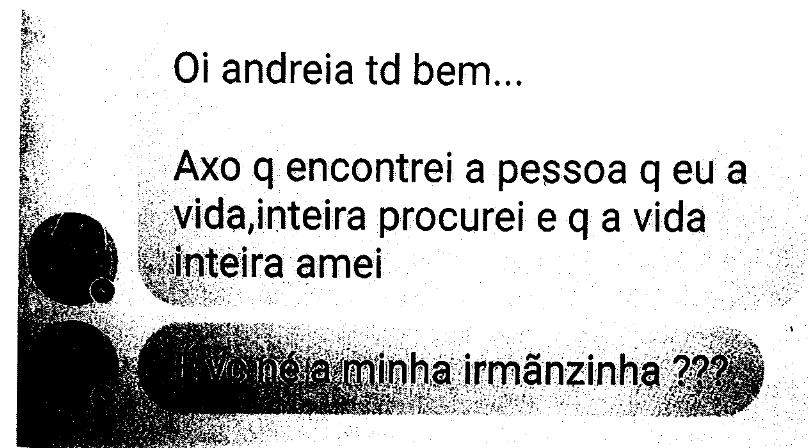

FIGURE 11.2 The sisters on Facebook, 2015

Adriana does not have Machado-Joseph Disease, Andrea told me. She has two children of her own and works as a supermarket cashier. "And what a coincidence," Andrea continued: "It was the Day of the Dead, and I had already bought flowers to take to my mother's grave."

The ethnographic memorial, an out-of-the-way effort to insist on the irreducible truth that a woman named Catarina Inês Gomes Moraes had once walked on the earth, was the site where the characters of the "tragedy generated in life" (in Catarina's own words) continued. In spite of all the time and prospects that people and institutions had taken from them, they continue to tell their family story, to live it a bit differently, and to graft each other anew: "It was there that we found each other, there in front of my mom's remains."

This is a photo Adriana took of Catarina's shrine, with the flowers she and her sister had brought. The sisters reached out to Adriano, who was now living by himself on disability benefits. With his disease progressing and conflict in the house, his wife left him for another man, taking the children with her. Adriano has found solace and support in the evangelical church he attends daily.

Catarina's scattered offspring were now forming the ties that she always imagined, and that had sustained her somehow: "to restart a home," she used to say. And now it was Andrea: "This is very important to me. What is happening is the brick that was lacking in my construction."

There was one more thing that Andrea wanted from the anthropologist who had "accompanied" Catarina's case: "Can you, please, tell me: what was my mom thinking in Vita?"

FIGURE 11.3 Andrea's photograph of the ethnographic memorial, 2015

FIGURE 11.4 Adriana, Adriano, and Andrea, 2016

I recalled Catarina's words: "In my thinking, people forgot me." But I didn't repeat her words, for Andrea was now living Catarina's hereafter. I told her I would love to meet the reassembling family and read parts of *Vita* and of Catarina's dictionary with them.

We met in January 2016 in Novo Hamburgo, the place of my own beginnings and departures.

It is such immanent negotiations (of people, social forms, time, worldliness, desire, storytelling and ethics)—in their impasses, stabilization, transience, excess, ruination, and creation—that animate the unfinishedness of ethnography and the critical work of human becomings.

NOTES

1 Greenblatt, "Tell My Story."
2 Biehl, *Vita*.
3 Berlant, "On the Case," 664.
4 Berlant, "On the Case," 670.
5 Berlant, "On the Case," 666.
6 Berlant, "On the Case," 669.