

## Ethics of Exhaustion

Most of the cancer patients I followed in Cali died during, or shortly after, my longest stretch of ethnographic research (2011–13). Some of them went through excruciating pain and anxiety in emergency rooms. A few died at palliative care facilities while health care practitioners pumped artificial calories through tubes inserted into their stomachs. Many others passed away at home while waiting for health insurance approval of their high-cost treatments. Of course, the puzzlement for me was not that a disease like cancer may kill patients. Rather, the surprise was that individuals with metastatic and terminal diseases would waste away while still getting aggressive, out-of-sync treatments.

Oscar, sixty-five, is one of them. Like other prostate cancer patients at HUV, his disease was detected in stage III, when the window of time for surgical removal of the tumor had already elapsed.<sup>1</sup> In addition to the belated diagnosis, he persistently complained of throbbing headaches. Following standard medical protocols, his oncologist, Dr. Zaya, put him on rounds of docetaxel,<sup>2</sup> hoping the tumor would recede. Yet the cancerous mass did not respond well to the prescribed medication; Oscar blamed it on the stress and exhaustion he constantly experienced. On top of that, his headaches grew more intense, an ominous sign the disease was, perhaps, far too advanced for a docetaxel-based chemotherapy.

After doing a bone gammagraphy,<sup>3</sup> Dr. Zaya confirmed that Oscar's headaches were, indeed, the unequivocal symptoms of a skull metastasis. The cancer was then reclassified as a phase IV malignancy, meaning Oscar had an incurable cancer. At such advanced stages, medical protocols encourage physicians to switch from aggressive (often cure-focused) interventions to palliative care, hoping to slow the pace of tumors' growth, control symptoms, and provide quality of life at the end of life.

Instead, Oscar was prescribed a second round of docetaxel as part of what is known in medical parlance as the docetaxel rechallenge. Typically, this chemo protocol consists in the reintroduction of docetaxel in patients who have achieved positive outcomes during an earlier encounter with this drug.<sup>4</sup> Yet Oscar's cancer had not responded to the medication. In fact, no reduction in tumor size or deceleration in its metabolic activity was observed.

Despite his aggressive and incurable cancer, the patient sounded optimistic about the new docetaxel round. While I was hanging out with him at the EPS office, he exclaimed, "This medication is going to help me. I am hoping it makes me live longer and keeps my cancer at bay. I want to feel better and do things I used to enjoy, like going to soccer matches at Pascual Guerrero or visiting family in Buga."<sup>5</sup>

I must admit that I was puzzled when therapeutic plans like his unfolded as if death was not on the horizon, as if there has been a shared agreement (often unspoken) that clinical interventions must continue, regardless of patients' bodily conditions and the emotional stress resulting from the burdensome medico-insurance bureaucracy.

Even though standard oncology protocols I reviewed do not recommend a docetaxel rechallenge for metastatic prostate cancer (NCCN 2019, 2020), Dr. Zaya had decided to stick to it. I understand protocols as a set of predetermined algorithms that regulate physicians' decision-making processes in clinical interventions (see Berg 1998). These are flowcharts of actions that allow physicians to gain information about bodies, to diagnose conditions, and to plan their therapeutic actions accordingly.<sup>6</sup>

When I asked Dr. Zaya about his decision to disregard standard protocols, he answered, "A good doctor should not feel constrained by the guidelines [protocols]. Sometimes it is necessary to think outside the box."<sup>7</sup> Dr. Zaya's plan for treating Oscar was based on a set of clinical algorithms that escaped the standardized oncology flowcharts. In fact, I contend, he engaged in counter-protocols, or aggressive (and highly toxic) treatments—typically used in earlier stages of prostate cancer—as a means of forestalling Oscar's death in the short term. At HUV, these kinds of practices were the norm rather than the exception.

Herein lies one of the central paradoxes of Colombian cancer care: while low-income cancer patients struggle to access chemotherapy on time,<sup>8</sup> when they finally do so the likelihood of reducing therapeutic efforts or transitioning into palliative care is often slim, even when cancers are metastatic. In the cases I witnessed at HUV, physicians felt they had a moral obligation to help their patients live longer, "recuperate" lost time, and bring a sense of justice to their lives, even if that meant resorting to counter-protocols that often inflicted more pain and suffering at the end of life.

To better illustrate these tensions, I consider the case of pain management in the context of the opioid crisis in the US. In his article, "Acute-on-Chronic" (2020a), Stonington describes opioid use as a mutual experience that fuels doctors' and

patients' determination to escape pain, "tangled with a biomedical drive to solve problems quickly" (229). The result is what he calls *emergency affect*, which is the "paradox of wanting to avoid opioids and wanting to escalate them" (229). As an affective force, thus, pain permeates medical decision making, "sometimes in directions contrary to expert recommendations or evidence-based protocols" (230).

In Colombian oncology, too, there is an emergency affect of sorts that pulls cancer patients, their families, and clinicians into counter-protocols that do not seem interested in resisting or reversing the cancer. At HUV, for instance, caring for patients who are locked in fights against cancer and the health care system unleashes an emotional whirlpool that pushes physicians in directions contrary to standard oncology protocols and notions of "good care."

According to Dr. Zaya, "We [physicians] are trained to act. Staying frozen, or overthinking things too much, is equivalent to letting patients die. We carry a lot of responsibility on our shoulders; we deal with a lot of stress and guilt." Oncologists like him, I contend, tend to engage in counter-protocols because they do not want to be held responsible for limiting patients' access to anti-cancer treatments, especially low-income patients who have fought so hard, and for so long, to secure access to these medical services. "Patients can still have a life with advanced cancer and should be informed about all the therapeutic options available," Dr. Zaya noted. "A metastatic disease is not synonymous with imminent death, assuming patients get access to the right treatments at the right time."

In this chapter I discuss how oncologists' desire to care for patients in a market-based health care system—entangled with the universal health mandate for universal health—shapes how the end of life unfolds. I analyze how physicians and their patients draw the line between *enough* and *too much* as the latter claim their right to health care while the former does not want to feel responsible for not providing all the treatments rendered possible by tutela writs.<sup>9</sup>

## EXHAUSTION

In an ethnography with disabled army veterans in the US, Zoë Wool (2017) coined the concept "in-durance" to describe a mode of waiting for rehabilitation therapies that her interlocutors experience as nonaction, "not a waiting *for*, but a waiting *around*" (79). In-durance, Wool writes, is "not the work of overcoming adversity, of moving on or moving elsewhere, but the practices of making do in a protracted moment of dire and even life-threatening uncertainty that seems so relentless it becomes ordinary" (80). In sync with Wool's thinking, Dwaipayana Banerjee (2020) proposed the term "ethics of endurance" to describe cancer patients' resilience in New Delhi, India, and their connectedness to the present amid adverse conditions for their survival. While *endurance* could indeed be used to describe the challenging (duress or harsh) experiences of many low-income cancer patients in Colombia, in this chapter I use *exhaustion* to refer to the weakening, stressful effects of endurance

and physicians' rationale for prescribing aggressive and out-of-sync treatments in the context of metastatic cancers—often pressured by patients and their families. Ethics of exhaustion points to an “ordinary” assumption in the biomedical world that dying from diseases like cancer can only be medically and morally acceptable when all aggressive interventions have been attempted, when vitality has been exhausted or drained from bodies, when life has been reduced to its limits of possibility.<sup>10</sup>

As ethics of exhaustion has grown increasingly quotidian because of the introduction of cutting-edge anti-cancer technologies—along with the promulgation of the right to health—it has also become largely unnoticed, like the air we breathe (see Kaufman 2015). As a result, cancer patients are often caught between inevitable bodily deterioration and aggressive treatments that are presented as their only salvation.

Under these conditions, therefore, it becomes “unreasonable” to question a physician's decision to prescribe a docetaxel rechallenge to a stage IV cancer patient. Patients may even run the risk of finding themselves in pain and alone as soon as they challenge their treatments.<sup>11</sup> “Not taking the therapy,” as Lochlann Jain (2013, 17) has written in her now-classic book on cancer in the US, “has something of a moral cast to it, as if it were an invitation to death by cancer, and for a doctor not to offer it for stage II, III, and IV cancers would constitute medical malpractice.” For Colombian physicians, unlike their colleagues in the US, getting sued for malpractice is not always one of their top concerns. Oncologists' anxieties at HUV seemed to have revolved around the emotional and ethical consequences of being unable to care for patients who have fought so hard and for so long to access anti-cancer treatments.

Underpinned by the tensions between a market-based health care system and the mandate to protect the right to health, I argue, accessing chemotherapy regimens is at once also the condition that renders these treatments out of sync and turns them into a concentrated poison. In other words, while low-income patients I worked with at HUV were not able to secure access to medical services early in their cancer journey, they did so via *tutelas* when their cancers were metastatic or terminal, that is, when standard oncology protocols would instead indicate the use of palliation.

When I asked Dr. Zaya to comment on what I perceived as an absurdity, he resorted to a popular saying. “El sistema no raja ni presta el hacha [The system does not allow you to cut wood or borrow the ax],” he said, shrugging his shoulders. The clinician had inadvertently distilled more than two decades of tensions between neoliberal health care policy and progressive legislation. This popular saying illustrates how patients systematically struggle to access their treatments when they should and get them when they shouldn't. This is partly what it means to be out of sync with the time of biomedicine (see chapter 1).

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Miguel, fifty-six, is a colon cancer patient from Tumaco, Cauca, in southwestern Colombia. When he was diagnosed in his hometown, metastatic cells had already

broken away from his 4 millimeter tumor and traveled into nearby tissues. Because of the scarcity of medical specialists in Tumaco who could treat him, Miguel was referred to HUV in Cali, where a section of his colon was surgically removed—along with several lymph nodes. Soon after the surgery, his oncologist prescribed capecitabine to kill any remaining cancerous cells in his body.

When I met him at HUV's oncology waiting room, a metastasis had recently been detected in his liver. The patient was put on a different chemotherapy regime that included the generics 5-FU, oxaliplatin, and irinotecan. Back and forth, here and there, doing vueltas or losing time,<sup>12</sup> Miguel had seemed determined to access all his treatments.

When I commended him for his resilience and determination, he responded, “Mijo, hay que hacerle [Son, I must do it]. Going back is not an option.” Miguel paused for a moment and then uttered one of the phrases that inspired this chapter: “I have no choice.”

Because he had kept detailed records of his clinical history and written proof of the frustrating interactions with the EPS and HUV, it was not difficult for Miguel to file a tutela writ and make the case that his incurable cancer was the result of systematic insurance delays and the hospital's lack of personnel. In less than a week a judge ruled in his favor, mandating Miguel's EPS and the hospital to take action and provide all his treatments without further delays. His physician, taking advantage of the recently granted legal provision, which guarantees the patient's full access to prescribed treatments, decided to switch the generic protocol for branded Zytiga.<sup>13</sup> The patient's tutela had paved the way for a relentless chemotherapy of life at the end of life.

Miguel carried on with his account: “I have the right to health.”

I furrowed my brows.

“Of course, every Colombian has the right to health care,” he uttered in a stern tone of voice, seeking to contend with my silent expression of skepticism. “I really mean it,” he insisted. “Thanks to the tutela my doctors are now able to prescribe whatever I need. The tutela is a kind of *comodín* [wild card]. The government pays for every treatment and drug I need. You see? I will keep requesting each and every treatment I have missed until I have enough *aliento* [strength]. I will do whatever it takes to keep fighting against my cancer, the government, and the health care system. If the hospital does not want to provide a surgery, then tutela goes! If the insurance happens to delay my treatments, then tutela comes! The health care system does work, but you got to fight it.”

For low-income, high-cost patients like him, achieving justice in the long term may justify pain and suffering in the short term. “So why not give it a try?” asked Miguel. “Hay que hacerle, mijo” [I gotta do what I gotta do, son].”

Echoing Kaufman's (2015) discussion about ordinary medicine, I contend that the *ethics of exhaustion* in Colombia becomes *logical and possible* for two main reasons. Eventually, most patients who file tutelas get unlimited access to their

medications. As a result, the tutela creates a sense of hope in an otherwise impossible future and normalizes aggressive interventions in the present as “the only way” moving forward. It is also logical and possible because the cancers growing inside patients’ bodies will metastasize and eventually kill their hosts unless a series of chemotherapy cocktails can be administered to prolong their life. Therefore, reducing therapeutic efforts, or rejecting them altogether, would be seen as an irrational choice, an unbearable defeat.

When I asked Miguel whether he would consider palliative care, he answered, “How am I supposed to ask doctors to stop my treatments? Doing so will kill me. This is not even a remote possibility. I am not quitting.”

For Miguel, palliative care did not seem to offer the array of technologies and treatments that oncology typically provides, which he had associated with “better care”—especially when the “wild card” of the tutela had granted him full access to anti-cancer medical services.

I argue that the tutela has tended to set the conditions in which patients’ (and their family members’) main priority is to confront the health care system, even if that means accessing treatments that may be out of sync with their cancer. Ethics of exhaustion, hence, becomes a seemingly rational impulse that normalizes an attitude of fighting and seeking access to aggressive interventions as the only options, paradoxically when cure is not possible. Therefore, getting more treatments until life is nearly exhausted—bringing it to its limits of possibility—becomes “the logical and right thing to do, the appropriate path to take” (Kaufman 2015, 43).

#### AMBIVALENCE

Unlike other senior oncologists I met at HUV, Dr. Masa was always available and willing to mentor junior physicians, as well as reassure conflicted anthropologists like me. The following conversation took place at a consultation room where Dr. Masa had met with Lucia, forty-eight, a stomach cancer patient. After reviewing her medical history, especially the notes he took during her latest visit to the outpatient wards, the physician offered a grim warning.

“We must act faster. If you don’t get your chemo soon, chances are you will end up with a colostomy for life. Let me be as clear as possible: Do you want to have a tube connected to your stomach?”

Lucia nodded in silence.

I could tell the patient was upset, yet unsure how to communicate her concerns to the doctor. She stayed silent.

The physician furrowed his brow and provided some practical directions for her: “Please grab all this paperwork [pointing to several sheets of paper on the desk] and take it to the insurance office. If necessary, yell at the office clerks, let them know you will sue them [via a tutela]!”

Dr. Masa was visibly irritated. He hit the desk with his fist, then grabbed a prescription form and wrote, “URGENT, life-threatening condition,” hoping the insurer would speed up the burdensome authorization process.

Without making eye contact with the physician, Lucia stood up and grabbed the insurance forms and prescriptions that were scattered on the desk. She turned around and left the room.

Before his next patient showed up at the door, I turned to Dr. Masa for clarification about this encounter. Given his hectic schedule and the large number of patients he sees per day at HUV, I quickly learned that I had to ask questions “on the spot” if I hoped to understand the complex interactions I witnessed. Conducting ethnography at HUV was becoming a matter of thinking and asking questions fast enough. The more I waited to debrief my puzzlement and confusion, the fewer details I would remember and the vaguer the physician’s answers would be.

“How do you go about this?” I asked the doctor.

“How do I go about what?,” he replied, visibly exasperated by my vague and sudden question. Putting my question on hold, he stood up and waved his hand at a clerk, who seemed fully absorbed in a cell phone conversation.

The physician exhaled heavily. Frustrated, he sat down. “Compadre, please do me a favor,” he asked me. “Would you mind looking for the head nurse and telling her to come? I want to know if they [hospital administration] are planning to fix the air-conditioning anytime soon! These consultation rooms have turned into boiler rooms. I cannot keep working like this.”

Grumbling and visibly upset, Dr. Masa sat down. He placed his right hand on his forehead and his right elbow on the desk, tilting his head slightly forward.

“What was your question? I am sorry, Camilo,” he said.

There was a prolonged silence in the consultation room. It took me a couple of deep breaths before I was able to articulate my ideas again.

“I guess I have a hard time thinking about all these patients, the patients I have come across at HUV,” I managed to say. “Most of them have metastatic cancers. They are literally rotting alive and struggling to catch up with their diseases. Some of them never come back to consultations. Those who return often do so because they have been granted a *tutela*—but then it is too late. So I am wondering about the ethics and medical protocols informing your decision to keep these individuals hooked up to aggressive chemo and whether their anti-cancer treatments should be complemented with other medical practices, like palliative care.”

Dr. Masa pulled out a white handkerchief from his pocket and dried the sweat that was dripping down his forehead and sideburns.

He checked his watch and explained, “All of these patients [pointing at the waiting room] are entitled by law to access the medical care they require. Few of them would ever be willing to give up on their fight against cancer and the unequal

health care system. They would do whatever they can to make the government pay for the lost time, even if that means filing tutelas to access treatments that would hardly benefit them.”

Dr. Masa’s words illustrate how oncologists like him are caught in a complex dilemma. On the one hand, they hope to prolong life by resorting to more technology and aggressive interventions, even if these actions may seem to go against their Hippocratic oath and evidence-based oncology protocols. On the other hand, they may feel they need to side with patients’ (and their families’) systematic struggle, which often means advising them on how and when to file tutelas, helping them bypass the EPSs’ bureaucracy, or harnessing the power of their professional and personal relations with pharmaceutical representatives.<sup>14</sup> Regardless, the general assumption is that permanent action and more interventions are the “right” and “logical” choices to guarantee patients’ right to health.

“I must be honest,” Dr. Masa said. “The thing is complicated.”

He stood up again and took a few steps inside the cramped consultation room. He continued, “We [physicians] are often caught between a rock and a hard place. Sometimes this is the result of naive misunderstandings or lack of honest communication between health care providers, patients, and their family members. Many people have bought into the idea that oncology—and medicine in general—is meant to cure, especially when diseases such as cancer are treated early. Even public health campaigns build on this assumption. But things are not as straightforward. Things are not black or white.”

Dr. Masa paused his explanation for a moment and peeked outside his office. After making sure no patients were standing nearby, he turned around and commented in a softer tone of voice, “Many, many cancers are not curable, especially when metastases have already occurred. Even cutting-edge technologies can hardly guarantee anything in the cancer world.”

I was disconcerted by Dr. Masa’s words. His explanation did not seem to match what he often tells patients in the consultation rooms. He contended that most cancers are fought with technologies that are either uncertain—in terms of their results—or too expensive for most patients. Yet physicians like him have chosen the ethics of prescribing generous quantities of the same drugs they feel ambivalent about.<sup>15</sup>

I made another effort to reformulate my initial question: “I guess I am wondering about what makes you keep prescribing more chemotherapy in the face of patients’ irreversible decay and imminent death.”

Dr. Masa replied with a question: “What would you do if you were in my shoes, Camilo?”

I felt caught off guard and unable to answer.

Disgruntled, the physician carried on with his response: “Look, I cannot just sit down and cross my arms. What else am I supposed to do?”

I frowned, as if trying too hard to come up with an answer.

Dr. Masa exhaled heavily, puffing out his cheeks, and added, “Should I tell them [patients] to go home because there is no hope? *Hay que hacerle* [We gotta do what we gotta do]. I cannot prescribe valerian drops or Bach flowers, administer a lethal dose of anesthetics, or have existential conversations about their [prolonged silence] . . . death. What kind of doctor would I turn into if I stop prescribing these chemo regimens? I would certainly be signing their death sentence, and I do not want to feel responsible for that. They have swum a long way to end up dying at the shore. Do you know what I mean?”

Dr. Masa seemed to be clear about the kind of doctor he is—or aspires to be. He is an action-driven and caring physician who staves off death by intervening in cancerous bodies through the variegated oncological tool kit at his disposal. Over the past twenty-five years he had been relying on chemo, surgery, and radiation as the main tools for killing or shrinking tumors. Therefore, efforts not directed at curing bodies and prolonging life may feel like surrender, even when patients are at the end of life. Slowing the pace of care or reducing therapeutic efforts would likely result in deleterious effects; patients’ lives and physicians’ own anxieties and professional reputation are at stake. Under these conditions, hence, wearing patients out is preferable to not doing “enough.” In other words, “sins of omissions are worse than sins of commissions” (Stonington 2020a, 236). A common figure of speech in medical ethics, this phrase may help explain why physicians like Dr. Masa and Dr. Zaya did not feel comfortable with presenting their patients with the option of reducing therapeutic efforts or transferring them to palliative care when their symptoms were still manageable.

Because patients and doctors have invested so much time and energy in securing access to medical services, reducing or refusing these services altogether may seem irrational, unfair, truly unthinkable—which is in line with the assumption that patients (and their doctors) have no choice.

Undoubtedly, oncologists at HUV keep doing their best to care for patients, reading pathology reports, palpating lumps, asking questions, filling out burdensome insurance forms and petitions. Yet, almost simultaneously, they acknowledge the frustration and impotency of being unable to properly treat most of their patients. Despite Dr. Masa’s intentions to quickly catch up with the time of tumors, he often fails—and he admits it. He grumbles, sweats profusely, exhales heavily, and puffs out his cheeks.

Dr. Masa’s reflections introduce a fundamental ambiguity in his oncology practice and reveal some of the ways in which his ethical structure unleashes its own reversal (see Whitmarsh 2008).<sup>16</sup> There is a conflict between what he thinks is right and what he feels he can, and must, do. And of course, it encompasses the frustration and impotency as the clinician tries so desperately to treat a disease that is often defined by its “unlimited and voracious growth” (Mukherjee 2012). For doctors like him, “good” cancer care may not only mean shrinking tumors, but

also taking patients to the limits of their lives. In Dr. Masa's treatment of cancer, it gradually became clear to me that the boundaries between concern and neglect, hope and despair, were getting constantly blurred (see Banerjee 2020).

Like Sisyphus, Dr. Masa has accepted pushing the rock of cancer up the hill, just to watch it roll back. Only when there is *nothing else to do* and cancerous bodies become dramatically deteriorated due to the disease itself and the aggressive (often out-of-sync) rounds of chemo, does dying become possible and acceptable.

#### PALLIATIVE ANXIETY

In this section I shift my ethnographic attention from resource-scarce HUV to Betania, a long-term care medical facility belonging to the private, cutting-edge hospital Valle del Lili. Surrounded by lush tropical vegetation on the outskirts of south Cali, Betania was conceived for patients who require either postsurgery rehabilitation before returning to their ordinary routines or symptom management on their way to dying. Although this medical facility has contractual agreements with insurers for the poor and unemployed (the subsidized regime), the patients I encountered during my visits were enrolled in insurance for the working class (the contributive regime) and the wealthier (prepaid).

Here I shadowed a palliative care physician during her rounds with terminal cancer patients.<sup>17</sup> I call her Dr. Soto. Her job is to make sure symptoms are under control and, on death's arrival, to make sure individuals are as comfortable as possible. Before interacting with patients and their family members, she would ask me to disinfect my hands by pressing on the antibacterial dispensers attached to the door frames of each private room. I was repeatedly reminded that any virus or bacterium could easily grow unchecked and kill most individuals at this facility.

Even though my observations soon became monotonous, the scenes I witnessed at this facility were no less difficult to bear. At each room I would come across mostly bedridden patients who were mildly or fully sedated, the majority of them connected to a wide variety of medical devices by means of urinary catheters, oxygen pipes, and nasogastric tubes. Impeccably dressed in blue and white uniforms, women nurses would constantly swing by the rooms. As part of their job, they must check on patients' vital signs, change bed sheets and diapers, document urine output, and administer painkillers such as Lyrica, hydromorphone, morphine, and tramadol, among others. Each room has a medium-size TV set hooked up to a metallic wall mount. The TVs remained on for hours; news broadcasts, talk shows, and lunchtime *telenovelas* (soap operas) created constant background noise that blended with the machines' beeping and the rushed footsteps of health care staff.

Eyes closed, Clemencia, seventy-eight, is lying on her back. The patient's bed is tilted at a 45-degree angle. Her hips are slightly flexed to prevent bed sores. To

aid in providing comfort and safety, several pillows and blankets have been tucked between her body and the bed's metal rails. When Dr. Soto and I entered the room, the patient's only daughter had just returned to check on her mother. A nurse warmly greeted her and shared the latest updates about Clemencia's overnight care. "It was rough for her," the nurse said, while caressing the patient's hands. "Her morphine dosage had to be increased to help her relax," she further explained. Throughout the last year Clemencia's stage IV esophageal cancer (esophageal squamous cell carcinoma, to be precise) had been treated at Valle del Lili's main hospital with a combination of surgery, chemotherapy (Herceptin), and radiation. Her prepaid insurance had given her—and her treating doctors—a wide range of therapeutic options to choose from. But her disease quickly became resistant to the prescribed treatments and metastasized to the liver.

The drugs and the cancer combined had exhausted Clemencia physically and emotionally, leaving her, her daughter, and the health care practitioners in a complicated situation. According to Clemencia's daughter, "One day they [physicians] informed us that all therapeutic possibilities had been exhausted, that it was time for palliative care. But, of course, I got upset. I felt like we were getting dumped—that the oncologist had given up on her. It felt like a punch in my stomach, you know. And I must be honest, it took me a long time to come to terms with the reality. Despite the different medical approach, they [physicians] assured me my mom would continue getting the best care possible until the very end. When cure is impossible, care is still possible, they told me."

A month before, when Clemencia was referred to this long-term medical facility, a team of palliative care givers, family physicians, respiratory therapists, and psychologists was brought together to help her cope with the disease. In addition, Clemencia was immunosuppressed because of the natural progression of the disease and the aggressive treatments she had been receiving. On top of that, she was having a hard time swallowing. While moving food or liquids into our stomachs is second nature for most of us, for Clemencia this action had turned into a risky practice due to her esophageal cancer. Echoing Jessica Zitter's (2021) detailed and gripping descriptions of her clinical work with dying patients at a hospital in the US, Clemencia's health care providers had pumped artificial calories directly into her stomach. These calories, however, often were accidentally pushed into her lungs. When that happened, Clemencia felt she was getting drowned or asphyxiated.

When she was classified as terminal and referred to this medical facility, her chemotherapy and radiotherapy sessions were halted. "But it was already too late to control her symptoms," noted Dr. Soto. "Most oncologists dump patients into palliative care units when they have exhausted all available options. They tend to focus on fighting the disease, shrinking tumors, extirpating masses. So by the time we get these kinds of patients—well, you know, they are embattled and weak.

So we must figure out how to manage the numerous side effects triggered by treatments and the natural progression of the disease.”

Health care staff at this facility were diligently trying to keep Clemencia comfortable, tinkering with pain medications and hoping to find effective and safe combinations for her. Too little morphine, and her pain would not be properly controlled. Too much of it, and a series of grave complications would be unleashed, which included constipation, urinary retention, and respiratory depression, among others.

“I can barely keep up with my mom’s treatments,” Clemencia’s daughter protested. “Not long ago I used to know exactly what [treatments] she was getting. But not anymore. The combination of the cancer, its symptoms, and her long list of medications is triggering side effects you can’t even imagine. It’s just so complicated. I feel physically and emotionally drained. That’s why I recently began spending the nights at home. I needed some rest.”

Indeed. Clemencia’s symptoms were out of control. And she did not seem to be “moving” in the sense of getting closer to regaining her independence or engaging in some of her favorite activities—like crocheting or tending her plants. She was, in fact, living on her way to dying. Her oral morphine had constipated her, so doctors temporarily stopped this medication and instead administered a laxative to induce her bowel movements. Drugs such as hydromorphone and Lyrica had been introduced at earlier stages, but Clemencia did not seem to tolerate them well. In addition, nurses would constantly swing by her room and puncture her veins to inject fluids. At this stage of cancer, every intervention, every drug, would unleash a series of side effects that medical practitioners had to be ready to counteract.

Two weeks after my initial visit to Clemencia, I was told she had been admitted to Valle del Lili’s ICU with nosocomial pneumonia.<sup>18</sup> As documented in her medical history, her pneumonia was the result of aspirated food that had caused an infection. Health care providers were quick to respond, however. Her oxygen levels improved after she was put on antibiotics. “That was hopeful news,” said her daughter. “We were still optimistic at that point.” Her mother, after all, seemed to be getting somewhere with her treatments—away from a life-threatening infection.

According to Dr. Soto, these complications are not rare in patients with esophageal cancer. After Clemencia’s ability to swallow was affected by the disease, she found it difficult to keep eating. To make things even more frustrating, patients like her who are enrolled in prepaid insurance plans may go in and out of medical facilities through what Zitter (2021) calls “revolving doors.” This is the back-and-forth between ICUs and long-term medical care that patients like Clemencia may suddenly find themselves caught in. Paraphrasing Zitter, as soon as physicians manage to cure one infection, the next in line attacks with vengeance.

Not much time passed before Clemencia was readmitted to the emergency room for another pneumonia. This time, however, her body was too weak. The

emergency physician inserted a feeding tube to prevent future infections of the respiratory tract. When I commented on Clemencia's case to Dr. Soto, she grudgingly mused, "Some of us [doctors] tend to think that a feeding tube is the right choice because it makes people live longer, especially patients who have tumors in their throat or esophagus. But this is not always the case; it may rather inflict unnecessary pain on patients and unleash a series of infections and injuries, which are especially difficult to manage. One of the most common problems is when their stomach contents escape up into the lungs, drowning them as a result."

Clemencia's team of physicians found themselves between the cancer's relentless growth and the rehabilitation protocols that were understood as the only and "logical" options for keeping her alive. Despite the risks and marginal therapeutic benefits, a feeding tube was finally inserted in Clemencia's stomach. Soon after, however, she was referred—once again through revolving doors—to Valle del Lili's ICU. While physicians desperately sought to contain the emergency, her daughter recounted, visitors were allowed to see the patient for a maximum of one or two hours per day. On top of that, they were required to wear personal protective equipment (PPE) to prevent exposing Clemencia to new and potentially lethal infections in her lungs.

This time, however, the patient did not return to Betania's palliative care facility. A more aggressive pneumonia won over her fragile immune system. Clemencia's "timely" treatments and her journeys through revolving doors, in part rendered possible by her prepaid insurance and her daughter's love, had morphed into a form of care that intensified pain and exhaustion while seeking to stave off death. Her case demonstrates (along with Juana's, discussed in chapter 3) that social class determines timely access to treatment and that even in resource-rich settings like Valle del Lili, patients and their family members experience high degrees of anxiety and pain as a result of prepaid insurance shaping how cancer treatments ordinarily unfold. It also highlights the common practice of referring patients—like Clemencia—to palliative care when their bodies are extremely weak and their cancers have metastasized throughout tissues and organs. Hence, managing cancer symptoms becomes an impossibility of sorts, a nearly futile and frustrating practice.

Situations like these are largely fueled by the ethics of exhaustion, a rationale that embraces the either/or dichotomy of curative treatment or palliation. What makes the ethics of exhaustion so insidious is that it enables caregivers to feel reassured that their actions are in sync with notions of acceptable morality (see Kaufman 2015). By increasing the number of prescriptions and providing more medical services—the conventional biomedical assumption goes (Dumit 2012)—we have a greater chance of defeating diseases and living longer. The faster clinicians act, and hence the longest therapeutic "distance" of patients, the longer they live.

This is the rationale associated with the ethics of exhaustion; while it builds on the *logical* and *right* decision to make patients live by doing more in the flow

of time (Stonington 2020b), relying on more aggressive treatments and technologies may only suspend the time of dying in the short term for the long term. This form of care, however, runs the risk of morphing into the mode of disregard and suffering experienced by Alice Rivières, a writer with the genetic mutation for Huntington's disease. In Rivières's personal account of her encounter with the testing technology for this condition (and its future-making capabilities), she noted that one of medicine's obsessions "is making sure that people do not die, or if they do, that is absolutely not medicine's fault" (2021, 33). This is partly what had informed Dr. Masa's and Dr. Zaya's rationale; they did not want to feel responsible for the death of their patients after all.

### SPEED

I conclude this chapter with a short reflection about speed and the reasons that aggressive interventions for metastatic cancer patients tend to have been transformed into "the only path" moving forward—on their way to dying. In what follows I set out to imagine a medical ethics not exclusively defined in terms of speed, or the need for being faster and "tougher" than cancer.

Here I echo the anthropologist Julie Livingston (2019) and her experimentation with parables, which she used to illustrate *self-devouring growth* in South Africa. In literature, a parable is a tool that provides meanings through the creation of parallels or comparisons. In the context of geometry, "parable" refers to a curve that resembles the path of something that is thrown forward and high in the air and falls back to the ground. In such a journey, Livingston (2019, 2) writes, "we travel out, unfolding the metaphor in a parabolic shape. By journey's end, we will have returned to the same plane in which we started, but somewhat further along the way, in the hopes of having learned something from our experience along the way." The reflection that follows travels out in a parabolic motion and unfolds along Lewis Carroll's *Through the Looking Glass*. By traveling out into this novel, my hope is that a parabolic journey will allow me to render visible some of the main assumptions about living with cancer in Colombia—and dying from it—that have become ordinary, just like the air we breathe to stay alive.<sup>19</sup>

In *Through the Looking Glass*, Carroll describes a scene in which Alice finds herself in a fantastical realm adorned with beautiful gardens. As she wanders, bewildered by the surreal landscape, she stumbles upon the Red Queen—a towering, human-sized flower that runs at an astounding speed. The Queen explains to Alice that the entire garden is, in fact, a gigantic chessboard, challenging her to a competition of speed. If Alice manages to move rapidly all the way to the final row of the chessboard, the anthropomorphic floral being vows to bestow upon her the title of queen.

The young girl accepts the challenge. She gets on her marks under the comfortable shade of a tree. When the Red Queen gives the signal, the girl starts running as fast as she can.

“Now! Now!” cried the Queen. “Faster! Faster!” And they went so fast that at last they seemed to skim through the air, hardly touching the ground with their feet, till suddenly, just as Alice was getting quite exhausted, they stopped, and she found herself sitting on the ground, breathless and giddy. The Queen propped her up against a tree, and said kindly, “You may rest a little now.” Alice looked around her in great surprise. “Why, I do believe we’ve been under this tree the whole time! Everything’s just as it was.” “Of course, it is,” said the Queen, “what would you have it?” “Well, in our country,” said Alice, still panting a little, “you’d generally get to somewhere else—if you ran very fast for a long time, as we’ve been doing.” “A slow sort of country!” said the Queen. “Now, here, you see, it takes all the running you can do, to keep in the same place.” (Carroll 1999, 32–33)

In this excerpt, Alice found herself in a dreamlike world where Newtonian physics or conventional logic did not seem to apply. Her desperate attempts at running and beating the Red Queen were not being translated into a meaningful change of position across the gigantic chessboard. Even though Alice ran as fast as she could, her position in relation to the nearby tree—the point of reference—did not change. In her desperate run, there was motion—her arms were rapidly swinging back and forth, in sync with every stride she took—yet there wasn’t a corresponding shift in space. While it took all her efforts to take rapid strides, she frustratingly remained in the same spot. Panting and near the brink of total exhaustion, Alice came to a rest and squatted under the shade of the tree.

What can this scene tell us about cancer care in general and the bizarre assumptions that sustain the ethics of exhaustion in Colombia’s market-based health care system?

Catching up with diseases such as cancer, and anticipating possible metastases, is what really holds oncology together. Caring for patients, hence, becomes a matter of speed,<sup>20</sup> being faster than a disease defined by its temporal urgency and self-devouring growth (Livingston 2012, 2019).

Yet getting faster access to screenings and anti-cancer medications does not necessarily give patients more time to live; it may often increase the time that transpires between diagnosis and death (Welch 2006; Esserman 2010; Mukherjee 2012)—which may lead to overtreatment of potential malignant lesions that probably would never have developed into life-threatening conditions.<sup>21</sup> Moving too fast along this path, hence, may prevent us from becoming aware of the conditions that have transformed “*hay que hacerle*” (we gotta do what we gotta do) into such a powerful single story,<sup>22</sup> a story in which cancer is presented as an external enemy that “unfairly” attacks our bodies, a story of struggle and fighting as the only and ethically right choice *moving forward*; a motion that often implies directionality and the hope of living longer.

This was Clemencia’s case but not only. Even though her radiotherapy and chemotherapy sessions had been suspended, Clemencia had gone back and forth between the ICU and the long-term care facility. She had endured several

nosocomial pneumonias, gotten drowned with aspirated food that lodged inside her lungs, and was connected to an artificial ventilator until her body was unable to withstand the next infection in line.

Prescribing more treatments and staving off death to cancer become the logical and right things to do, until death has become an all too obvious presence. While oncologists I worked with sought to care for patients and prolong their lives, part of that means practicing counter-protocols that may arguably inflict more pain and suffering—shortening patients' lives as a result. In Oscar's case, for instance, his oncologist prescribed a second round of docetaxel, even though the first attempt was unsuccessful at shrinking the tumor. For Miguel, once he was granted a tutela, his oncologist felt compelled to "regain" some of his lost time by switching the prescription from a generic cocktail of drugs to Zytiga. Both the patients and their family members would spend their last days doing burdensome paperwork while the patients received aggressive anti-cancer treatments.

In this chapter I explored terminal cancers at different intersections of biomedical and health insurance practices, hospital infrastructure, and ethical standpoints that push physicians and patients (and their family members) into a relentless chemotherapization at the end of life—largely because "there is no choice." Recall my conversations with Dr. Masa. While he acknowledged that most chemotherapy regimens would hardly benefit patients, he kept prescribing the drugs on a regular basis. This seeming ambivalence reflects how procedures and treatments that are usually considered risky and unnecessary by standard biomedical protocols become ordinary.

How could terminal cancers be rendered more die-able and, above all, transformed into a healing experience, especially for patients (and their families) who have been caught between relentless fighting, the disfiguring effects of cancer, and agonies? These are the questions I set out to explore in the epilogue of this book.