

Epilogue

Emancipatory Futures

Synonymous with “mob,” “throng of people,” or “social uprising,” *tropol* has come to shape the intersections of health care in neoliberal Colombia. In my mind, *tropol* evokes images of individuals waiting patiently at health insurance offices while being irritable enough to yell at representatives, hopping on intermunicipal buses, and enduring endless road trips, clutching hard copies of their clinical histories and being ready to file tutela writs to protect their right to health.

For many cancer patients I met at HUV, the slogan *sin tropel no hay salud* (no fight, no health) was more than a rallying cry shouted by protesters marching down Calle Quinta, or a mere set of graffiti sentences written on public hospital walls. It was, in fact, a powerful mantra that redefined the goals of care and the meaning of treatments. As such, the stories of cancer patients and their families presented throughout this book are not so much about their will to live (see Biehl 2009) as they are about their persistence to become visible before a state that has systematically neglected them. Gaining access to anti-cancer treatments, I have argued, becomes a vindictory practice in and of itself, regardless of the outcome. The point of gaining access to treatments is to exercise one’s rights.

While *tropol* has allowed patients to access medical services, often via tutela writs, however, it also has the potential to inflict more pain and suffering in the long term—at the end of life. Consider *tropol* in the context of acute inflammation. Physiologically speaking, inflammation is an organic process by which our bodies’ immune system readies itself for action, seeking to protect us from elements that are perceived as threats—such as bacteria and viruses. Once the perceived threat has been eliminated, our immune system scales back its defensive activity, thereby allowing the body to repair its tissues (e.g. grow healthy cells to replace dying or

diseased ones). While inflammation is beneficial for short periods (Dai et al. 2020), once it becomes chronic the body loses its capacity to heal and grow new tissues, setting the right environment for the development of a wide range of conditions, from Alzheimer's disease and heart disease to diabetes and various forms of cancers (Kinney et al. 2018; Sorriento and Iaccarino 2019; Coussens and Werb 2022).¹

Similarly, the ever-present tropel that has motivated patients to join protests and endure exhausting vueltas (Sanz 2017), for instance, may be the same impetus that normalizes aggressive interventions as “the only way” moving forward (see chapter 5).² When cancers become terminal or metastatic, patients who have managed to access treatments via tutelas tend to be more focused on keeping these same services rather than reducing therapeutic efforts or transitioning to palliative care.

Dr. Artesano once complained during his palliative care consultations at HUV, “These patients are fantasizing about an imaginary future instead of placing their attention on what is happening with their disease processes right now.” Similarly, tropel seems to have acquired the bizarre potential to remove patients from their present situation—a seriously deteriorated body—and direct their attention to an uncertain future that increases their anxiety.

At the same time, I came across many oncologists who were engaging in counter-protocols,³ largely because they did not want to feel responsible for patients' deaths, especially the death of individuals who had fought so hard and for so long against EPSs, hospitals, and pharmacies. Under these circumstances, reducing therapeutic efforts and wasting away from diseases like cancer become justifiable only when biological life has been exhausted and taken to the limits of possibility.

Instead of calling for more effective strategies to diagnose and treat cancer early,⁴ or mentioning the importance of guaranteeing equitable and prompt access to anti-cancer treatments, dismantling EPSs, and protecting the rights to life and health of all Colombians—all of which are much needed interventions—I end this book with a different kind of proposal. I envision the epilogue as an opportunity to participate in new exploratory attempts at “softening” cancer care paradoxes and composing newly arranged spaces in which to live on our way to dying.

Doctor R. M. Rajagopal is my muse. He is the pioneer of the palliative care movement in India and a Nobel Peace Prize nominee in 2018. During conversations I had with him in 2009, when I was still in the first years of my PhD program, the physician alluded to his medical practice as being “high-touch.” According to him, this is a simple, low-cost, yet effective medical approach for patients who are in physical and emotional distress while also being a powerful practice for counteracting the disease-oriented medical paradigm. By engaging in a high-touch approach—sitting next to patients (and their family members), listening to them, caressing their dying bodies, and administering low-cost oral morphine—he and his medical team in Kerala, South India, have been providing comfort and symptom control for low-income cancer patients at the end of life. Their work has shown

that simple and low-cost interventions can have profound effects on patients' quality of life. "In palliative care," he explained to me, "we do *touch* patients a lot, as human touch does have a therapeutic effect on the human being. In palliative care that *touch* symbolizes humanity. It is about managing pain, healing emotions, and lessening suffering."

Similarly, seeking to counteract the perverse effects of a neoliberalized health care system and the ethics of exhaustion, I argue, is not only about improving access to medical services that enhance and prolong life, as the current health care reform aspires to do. It is about having alternatives beyond fighting for the right to receive care ("sin tropel no hay salud") but also to *refuse* it. Hence the proposal to understand cancer not only as a defect, but as a condition that we may have to live with and die from. My hope for those who choose to continue getting aggressive and out-of-sync treatments and engaging in ever-present tropel is that their decision does not respond to the fear of the painful and disfiguring consequences of diseases like cancer.

Clinical studies have shown the effects of therapeutic touch and palliative care on cancer patients (Tabatabaee et al. 2016; Gentile et al. 2021). In 2010, for instance, a group of researchers led by Jennifer Temel found that patients with terminal lung cancer who transition to palliative care immediately upon diagnosis not only were happier, more mobile, and in less pain as the end neared; they also lived nearly three months longer than patients who underwent aggressive chemotherapy. Although this study could not determine why the patients lived longer, the authors and other experts had several theories: depression is known to shorten life, and patients whose pain is treated often sleep better, eat better, and talk more with relatives.

Furthermore, introducing palliative care earlier, even when curative measures are ongoing, may reduce hospital and emergency room costs. This means reducing patients' unnecessary visits to the hospital, so it may be cost-beneficial for both patients and insurance companies. If patients' symptoms are controlled, they (and their family members) won't feel the need to rush into an emergency room where they will be treated through invasive and aggressive biomedical protocols.

Yet the mere act of *slowing down* may be counterintuitive in the context of voracious diseases like cancer. Even though most major hospitals in cities like Cali have palliative care units,⁵ the transition from oncology to palliative medicine is often difficult, let alone attempts at integrating these two approaches in standard cancer care. While low-income patients struggle to access expensive and uncertain treatments that may be out of sync with the time of cancer and the decaying conditions of their bodies, they simultaneously struggle to get palliative care services, not because these are necessarily expensive, but because they often are, paradoxically, low-cost.

A fully integrated "high-touch" palliative care approach may help patients who are systematically confronted with the double bind of a disease of self-devouring

growth (Livingston 2019), on the one hand, and an economy of unlimited growth, on the other. It may offer an alternative for many of us who have ever been (or will be) caught up in the dilemma of getting heroic/aggressive treatments that may kill us but that are presented as the only solution or refusing these interventions just to face prolonged and painful deaths. Dr. Rajagopal's high-touch approach has enormous potential for "softening" the seemingly unresolvable paradoxes of cancer care in Colombia (and elsewhere), where the legal, bureaucratic, and financial practices created to guarantee access to anti-cancer treatments reproduce the same problems they were created to solve in the first place.

Admitting the inevitability of cancer deaths may help make this disease "livable and dieable." After all, as Jain (2013, 223) has written, "cancer has to be okay for people who are dying." Conversely, I would add, dying must also be rendered more thinkable and visible as part of our own therapeutic journeys. It is by "lathering" our ideas and assumptions about it, or "taking them up again over time from various perspectives and thus lending them consistency" (Solhdu 2021, 127), that a thickness of their own may eventually be possible.

Here I draw inspiration from the powerful story of Alice Rivières, who in 2006 took a genetic test that foretold she would eventually develop Huntington's disease. In her first-person account of the revelation of her test results, Rivières (2021, 31) shared her multiple encounters with the biomedical sphere and its "power to transform humans into medically conforming creatures." Her test results pushed her into a double bind: disease, on the one hand; medicine, on the other. Feeling unable to disentangle herself from biomedicine's overwhelming labeling process and singular forms of truth, it occurred to Rivières that suicide was "the only alternative with enough power, counterpoint, and emancipatory freedom" (34). Even though her anguish would later unfold into what she now calls "neuro-revolutionary metamorphosis," as well as the starting point for the Dingdingdong project—a collective dedicated to coproducing knowledge about Huntington's and pushing thinking further—I want to pause and highlight her initial rumination about suicide.

Her seeming despair, I believe, could be used as an excuse for considering the healing and emancipatory potential of euthanasia—a kind of suicide, with assisted dying being one of its most common iterations in Colombia. This is a medical practice that hastens the death of a person "at the person's request, by means of an easy, painless and peaceful passing" (Mendoza-Villa and Herrera-Morales 2016, 326).⁶ While legal in Colombia since 1997, euthanasia was thrown into legal limbo until 2015, when the Supreme Court asked the Ministry of Health to create much-needed guidelines for petitioning, assessing, and performing euthanasia. To date, however, euthanasia remains largely available to well-off patients who have the means and social capital to bypass the highly bureaucratic guidelines set by the government.

Inspired by Mara Buchbinder's *Scripting Death* (2021), I am not suggesting that euthanasia should be transformed into the default public policy for cancer patients

who have metastatic diseases and who are often caught in exhausting trol. This would be an oversimplistic and perverse rationale, to say the least, which would imply that it is easier to just die from cancer than to attempt to fix a dysfunctional health care system. It is worrisome that precarious living conditions and institutionalized systems of exclusion may bring terminally ill patients to the point where they wish to die. Rather, my intent is to consider practices of care at the end of life, especially for people who do not consider life as biological deterioration or who have been caught between incurable diseases and aggressive treatments. And, of course, guardrails must be kept in place to avoid the abuse of pressure on doctors or families to end lives prematurely from insurance companies eager to reduce expenses. Without such protections, it is not difficult to imagine whose deaths would be financially justifiable.⁷

I want to be clear. There are useful aspects of biomedicine and the health care system currently in place in Colombia. Both have saved many of our lives and improved the lives of people that you and I love, after all. In this book I have sought to present a reality in which many of us are dependent on these systems, even as we simultaneously try to build alternatives to them. Current government efforts directed at promulgating national health care reform are complex endeavors, rife with contradictions. And we must be prepared to run into deeply held assumptions—blind spots—that will need to be questioned, exposed, and dissolved. By responding to Rivières's (2021) call to use her Huntington's disease to push thinking further, my hope is that the paradoxes of cancer care described in this book will help us explore and facilitate conversations about emancipatory practices for living on our way to dying, and, to the degree possible, to dying with one's dignity intact.