



Fraught with Pain:

Access to Palliative
Care and Treatment
for Heroin Use
Disorder in
Colombia

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WORKING PAPER 6

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Contents

ACKNOWLEDGMENTS	9
INTRODUCTION	13
The Importance of Understanding How Drug Control Policies and Access Barriers Affect People Who Use Drugs and Those Who Suffer from Pain	16
Methodology	19
The Book’s Structure and Some Conceptual Clarifications	25
CHAPTER 1. THE STATE’S RESPONSE TO PAIN: CHALLENGES TO ENSURING THE AVAILABILITY OF OPIOID MEDICINES	29
Opioid Medicines: Straddling the Divide between Essential and Controlled	33
Opioids in Palliative Care	40
Heroin Dependence and Treatment with Opioids	45
The Right to Health in Colombia and Its Relationship with the Regulation of Opioid Medicines ...	52
CHAPTER 2. LIVES ON THE MARGINS: HEROIN USE AND THE SEARCH FOR TREATMENT IN COLOMBIA	59
The “Big H” in Armenia, Pereira, Cali, Santander de Quilichao, and Cúcuta	61
Legal and Policy Response toward People Who Use Drugs	72
Access to Methadone Maintenance Therapy	82
Barriers to Accessing Health Services and Their Impact on the Human Rights of PWUD	95

CHAPTER 3. PAIN’S REVOLVING DOORS:	
THE DISTANT PROSPECT OF PALLIATIVE CARE	113
The Need for Palliative Care in Colombia	114
Legal and Policy Response toward	
People in Need of Palliative Care.....	121
Access to Palliative Care	130
Barriers to Accessing Palliative Care.....	144
CHAPTER 4. TOWARD HEALTH	
CARE FIT FOR PAIN RELIEF	151
Some Final Considerations.....	152
Overarching Recommendations.....	156
Recommendations concerning	
Pain Relief in Palliative Care	160
Recommendations concerning Pain	
Relief for People Who Use Heroin.....	161
A Future Research Agenda on Colombia’s	
Response to Pain Relief	163
GLOSSARY	167
REFERENCES	169
ANNEX. List of Opioid Medicines in Colombia.....	176

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INTRODUCTION

For as long as human beings have existed, we have felt the need to alter our consciousness and mental functioning, control our emotions, and alleviate the pain associated with illness.¹ The first evidence of this age-old relationship between the human species and psychoactive substances involves opium poppies and their derivatives. Traces of poppy were found among human remains in northern Italy and Switzerland in the prehistoric Stone Age. Poppy use was also recorded in 6000 B.C. by the Sumerians, who cultivated the poppy plant and extracted its juice; and the same occurred in India. The Greeks praised the power of this plant to make people forget their sorrows and not feel even the most severe pain. Uses of poppy derivatives were both medicinal and recreational, and they were common in India, China, and the Middle East. By the sixteenth century, poppy consumption had become popular in Europe (Brailowsky 2002, 169, 282–3).

The international drug control system, which nations have committed to since the twentieth century, is rooted in the aim of a “drug-free world,” which is humanly impossible, given that the pursuit of pleasure and altered states of consciousness through drugs, art, and other means is an intrinsically human desire. According to some archeologists, early civilizations grew grain for beer, not food. The truth is that we have yet to discover a single society in all of human history that has existed without consuming drugs (Szalavitz 2016, 22).

1 Humans are not unique in the animal world for our attraction to psychoactive substances. Many animal species feed on fermented, overripe fruit because of its high sugar content, which produces an inebriating effect (Brailowsky 2002, 144).

The opioids that are regulated at the international level are a source of relief for people experiencing severe pain and physical and mental suffering. In particular, drugs derived from opium, such as morphine and methadone, provide relief for two populations in situations of suffering: (i) people at the end of life who need palliative care and (ii) people who have a heroin use disorder and who require opioids as part of their treatment.² For such individuals and their loved ones, these situations call for health policies based on respect for human dignity and autonomy.

This book focuses on two groups of opioids: those used to treat pain and those used to manage withdrawal symptoms and for maintenance therapy for people suffering from heroin dependence.³ The first group includes opioids such as morphine, hydromorphone, oxycodone, buprenorphine, fentanyl, and methadone. In the second group, the only substance used in Colombia for this aim is methadone, although other countries also use buprenorphine (whether alone or in combination with methadone) or pharmaceutical-grade heroin.

The international drug control system for psychotropic substances has designated these drugs as “narcotics,” which is derived from the Greek word *narkoyin*, meaning numbness. As psychotropic substances, they act on the central nervous system, affecting basic neurological functions such as respiration and feelings of pleasure and pain. Morphine—the most well-known opioid—was first isolated in 1803 and was named in honor of Morpheus, the god of sleep and dreams. Meanwhile, heroin—a more potent derivative—was first synthesized in 1874 (Brailowsky 2002, 123, 286). In 1915, the first opioid antagonists were synthesized. This is extremely important in light of opioids’ capacity to cause respiratory depression and even death; an antagonist serves to reverse this effect (ibid., 130).

Opiate receptors in the brain—that is, humans’ own opioid systems—were discovered in 1973 (ibid., 130). Opioids’ power over the human body lies in the fact that they affect natural neurological processes responsible for who we are and what we feel. As Gabor Maté explains, drugs influence and alter the way we act because they mimic our brain’s

2 In addition, people with chronic pain may need opioid medicines to alleviate their suffering, and therefore are also affected by the international drug control regime. However, this book does not address the barriers faced by this population when accessing such medicines.

3 For more information on the various uses of opioid medicines, see Brailowsky (2002, 136–7).

natural chemicals, which allows exogenous opioids such as morphine to occupy receptor sites and interact with our central nervous system (Maté 2010, 157).⁴ It is for this reason that opioids are critical for effectively treating pain in palliative care patients and for treating withdrawal symptoms among people with heroin dependence.

The international drug control system is at the center of this issue, for while global drug control policies aim to secure a “drug-free world” through criminalization, eradication, and enforcement, they have done little to ensure a world in which controlled substances are available to those who require them for medical purposes (Global Commission on Drug Policy 2015). Indeed, the United Nations Special Rapporteur on the Right to Health signaled in his 2010 report on the international drug control system that “explicit consideration of human rights is absent in the treaties and has lacked priority among the implementing bodies” (Grover 2010, para. 11). He also emphasized that in cases where the international drug control regime and international human rights regime conflict with each other, countries’ human rights obligations should prevail (*ibid.*, para. 10).

In this way, drug policy often violates human rights, particularly the right to health, both for people who use drugs (PWUD) and for those who need these substances for end-of-life care.⁵ As explained in detail in the following section, this book analyzes the impacts of drug policy on these two populations. Our central aim is to explore the ways in which the Colombian health system and the enforcement of drug laws in Colombia violate these two groups’ fundamental rights, especially their right to health, in five specific cities by imposing barriers to opioid access. We also present a set of public policy recommendations aimed at overcoming

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- 4 This is the case for more than just opioids: the human brain also has an endocannabinoid system, whose receptors process cannabis compounds, as well as a dopamine system, whose receptors react to stimulants such as cocaine (Maté 2010, 152).
 - 5 “Criminalization of drug use and possession are implicated in violation of several human rights, including the right to health. Other infringements of the right to health are less direct, but occur as by-products of the skewed focus of the international drug control regime: for instance, insufficient access to essential medications. The Special Rapporteur considers that each of these violations is traceable ultimately to a disproportionate focus on criminalization and law enforcement practices at the expense of the enjoyment of the right to health and reduction of harms associated with drugs” (Grover 2010, para. 18).

these obstacles and ensuring access to the opioid medicines required for these two populations to live with dignity and free from pain.

The Importance of Understanding How Drug Control Policies and Access Barriers Affect People Who Use Drugs and Those Who Suffer from Pain

Analyzing the enjoyment of the right to health by two different populations—people who use heroin and patients suffering from terminal illness—would seem ill advised, for what does the experience of someone dying from cancer have to do with that of someone who suffers from the problematic consumption of an illicit substance? The lives of these two groups of people seem so unlike each other that we would expect their joint analysis to reveal more differences than similarities. However, the experience of pain, on the one hand, and withdrawal symptoms, on the other, share many more challenges and solutions than one might imagine. In both cases, the right to health is violated by the limited access to and availability of opioid drugs, and for both groups it is critical that approaches to care seek ways to improve the quality of life of those who suffer from these conditions, even if a “cure” is not possible.

These two populations, though living in different worlds and realities, have much in common. To mention just a few shared traits: they are both in need of the same controlled medicines; they both require interdisciplinary treatment that extends beyond opioids; they both seek health services during moments of extreme vulnerability; and they are both often treated negligently by health systems that are ill equipped to handle death and drug dependence.

Our study is guided by the need to link discussions on the right to health with those on drug policy reform. The populations we talk about here are the ones most in need of a change whereby drug control measures cease to stand in the way of pain relief—but we realize that the barriers are many and are deeply permeated by stigma.

The stigma attached to opioid consumption leads to serious impacts on the right to health and the right not to be subjected to cruel, inhuman, or degrading treatment. Opioids alleviate severe pain, and denying these substances to patients can cause unimaginable suffering. Opioids are also valuable for the treatment and recovery of people who wish to overcome

their heroin dependence; as a result, limiting their access to these medicines places these individuals in a situation with no way out.

In a recent report on the impact of the world drug problem on the fulfillment of human rights, the United Nations High Commissioner for Human Rights points out that the international drug control system—which criminalizes virtually all actions relating to illicit substances—has had a negative impact on the right to health, the right to life, and the right to due process and has exacerbated discrimination against women, ethnic minorities, children, and indigenous peoples. With regard to the right to health, the report emphasizes that even in countries where the use of drugs constitutes a criminal offense or carries administrative sanctions, PWUD have the same rights as anyone else and thus have the right to receive medical treatment under ethical standards that include the patient’s right to make decisions about treatment (United Nations High Commissioner for Human Rights 2015).

Furthermore, access to controlled essential medicines is limited or altogether absent in many countries due to governments’ fear that these substances will be diverted toward illicit markets, which leaves millions of people in a state of suffering. In this regard, the High Commissioner for Human Rights makes the following recommendation to governments:

The right to health should be protected by ensuring that persons who use drugs have access to health-related information and treatment on a non-discriminatory basis. Harm reduction programmes, in particular opioid substitution therapy should be available and offered to persons who are drug dependent, especially those in prisons and other custodial settings. Consideration should be given to removing obstacles to the right to health, including by decriminalizing the personal use and possession of drugs; moreover, public health programmes should be increased. The right to health requires better access to controlled essential medicines, especially in developing countries. (United Nations High Commissioner for Human Rights 2015, para. 61)

Colombia’s debate over drug policy reform has focused on reducing illicit crops and combatting drug trafficking. Our book seeks to study two populations largely overlooked in this discussion: those in need of palliative care and those who require treatment for heroin dependence. These groups have not been the traditional faces of the movement in favor of

policy reform, nor of research studies on populations affected by Colombia's drug policy, even though they too have been affected by the war on drugs and its focus on oversight and control, as well as by the collateral effects of drug prohibition, including stigma.

Despite the inattention to the right-to-health impacts of Colombia's drug policy in discussions on drug policy reform, certain advances have been made in international settings. In 2016, the international community adopted an outcome document for the United Nations General Assembly's Special Session on the World Drug Problem, better known as UNGASS. This drug policy consensus entitled *Our Joint Commitment to Effectively Addressing and Countering the World Drug Problem*, contains two pillars that are particularly relevant for this book. First, it provides operational recommendations on the measures that states should take for the treatment of drug use disorders, acknowledging the complexity of the problem, the need to rely on evidence-based programming, and the importance of cooperation with civil society initiatives. Within this pillar, it also calls on states to take necessary measures to treat opioid overdose as part of their efforts to reduce drug-related mortality.

Second, the document contains a section on access to controlled medicines, entitled "Operational Recommendations on Ensuring the Availability of and Access to Controlled Substances Exclusively for Medical and Scientific Purposes, while Preventing Their Diversion," which urges states to simplify and streamline distribution channels for these substances in order to remove excessive restrictions.

Meanwhile, the punitive nature of the war on drugs is constraining the achievement of the Sustainable Development Goals (SDGs) in that it overlooks the task of reducing the harms associated with drug use. Governments' pursuit of policy coherence between the SDGs and the operational recommendations of UNGASS is thus an additional scenario in which the health of people who use drugs is at play. Countries that have already submitted their voluntary national SDG reports—such as Colombia—would benefit from the addition of SDG indicators related to drug policy, a task that requires different metrics that go beyond simply measuring the number of PWUD to measuring more relevant and profound issues related to the living conditions of this population. Collecting crude data on the prevalence of drug use without considering the context in which it occurs, the health consequences for PWUD, or the impacts

on public health offers little meaningful guidance for lawmakers (International Expert Group on Drug Policy Metrics 2018, 4).

The International Peace Institute maintains that aligning the two agendas—that of drug policy and that of sustainable development—offers two clear benefits: (i) it can help overcome the limitations of effective drug policies that stem from suboptimal metrics for measuring these policies' impact, and (ii) it can allow drug policies to improve, rather than hinder, efforts to achieve the SDGs (*ibid.*, 3).

Against this backdrop, Colombia's legal framework—namely the Statutory Health Law (Law 1751 of 2015), the Palliative Care Law (Law 1733 of 2014), and the Law on Care for People Who Use Psychoactive Substances (Law 1566 of 2012)—protects the right to health of PWUD and people in need of palliative care. Nonetheless, the reality on the ground is far from the law on paper, calling attention to the need to better understand the obstacles faced by people who need opioid medicines in Colombia and how they can be overcome.

The availability and use of opioid medicines,⁶ which is the focus of this book, has grown in Colombia thanks to increased palliative care services and methadone maintenance programs for people who use heroin. But despite the recent upswing in these medicines' availability, the supply of palliative care services and heroin dependence treatment—which are an indicator of effective access to these medicines—is insufficient to meet demand, as we will explain in chapters two and three.

Methodology

Research for this book was carried out between May 2017 and September 2018. During the first few months, we conducted interviews with experts in the fields of psychotropic substance use and palliative care,⁷ with the objective of understanding the basic principles behind the use of opioids in palliative care and behind the use of methadone in maintenance therapy. Moreover, in light of these professionals' backgrounds, our interviews

6 According to the US National Cancer Institute (2018), an opioid is “a substance used to treat moderate to severe pain.” Unlike opiates, which are naturally derived from opium poppy, opioids are synthetic or semisynthetic. Despite this scientific distinction, we use the term “opioid” to refer to any kind of opioid or opiate that can be prescribed for pain relief or maintenance therapy. See annex.

7 Pablo Zuleta, Julián Quintero, Yanina Silva, Marta Ximena León, and Inés Elvira Mejía.

allowed us to identify key contacts for our visits to the cities. We then collected information through field visits to the five selected cities, where we visited a range of health facilities and conducted pre-arranged interviews with their staff.

To select the five cities that would be our object of study, we analyzed data from *Heroin in Colombia*, a national study published by the Ministry of Justice in 2015 (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015). This study identifies seven cities as the only cities in Colombia with established heroin use: Bogotá, Medellín, Cali, Santander de Quilichao, Pereira, Armenia, and Cúcuta. We selected these cities as reference points, as we hope that this book will contribute to the forging of alliances between organizations working on behalf of PWUD and those working in the area of palliative care. Thus, it was more convenient to analyze and compare the two population groups in the same geographic area. For the seven preselected cities, we then researched the availability of palliative care services. Bogotá, on account of being the country's capital and the site of existing palliative care training for health care personnel, has more palliative care services than the other cities. Meanwhile, Medellín is home to the country's first pain clinic and also has a large number of accredited facilities.⁸

In light of these two cities' advances in the palliative care arena, as well as the capacity of endogenous organizations and universities to carry out diagnoses similar to ours, we decided to eliminate them from our list. Furthermore, we found that the remaining five cities offered unique dynamics for observing specific phenomena, such as inter-city relationships and the impact of migration on access to opioid medicines. With regard to inter-city dynamics, Cali/Santander de Quilichao and Pereira/Armenia are two sets of cities whose residents are constantly crossing into the other to access goods and services, especially health services; therefore, studying the cities together provides useful data. Meanwhile, in terms of migration, Cúcuta—which sits on the border with Venezuela—offered the chance to research the enjoyment of the right to health among migrants and refugees in need of opioid medicines. Our five selected cities were therefore Cali, Santander de Quilichao, Armenia, Pereira, and Cúcuta.

⁸ We obtained information on accredited services from the Special Registry of Health Service Providers. See <https://prestadores.minsalud.gov.co/habilitacion/>.

In order to identify the health service provider institutions (*instituciones prestadores de salud*, or IPSs) that we would visit and whose staff we would interview, we referred to the Special Registry of Health Service Providers,⁹ which is the official database containing all IPSs accredited to provide services within each medical specialty, according to department, city, and type of service.¹⁰ Based on this information, we created a database of relevant actors that we then supplemented with service providers that we identified online and through recommendations from our earlier expert interviews.

We conducted our city visits between October 2017 and February 2018. In each city, we interviewed the following key actors: staff of departmental and municipal secretariats of health,¹¹ staff of Regional Narcotics Funds, health professionals in the various IPSs accredited to provide palliative care and drug dependence treatment, workers from community centers and “listening centers” for people in street situations, individuals who use heroin, palliative care patients, and family members of these last two groups. In each city, we also attempted to interview representatives of health benefits management companies (*entidades administradoras de planes de beneficios*, or EAPBs)—previously known as health promoting entities, or EPSs—but in most cases, our requests were ignored. For the IPSs, we were unable to interview all of the facilities that appeared in our database for a variety of reasons, including IPSs’ failure to respond to our requests, difficulties in scheduling a meeting, and our limited resources for fieldwork.

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- 9** Within this registry, the identification code for palliative care is 309 (*dolor y cuidados paliativos*, or “pain and palliative care”). For drug use disorders, there are three relevant codes: 123 (*atención a consumidor de SPA paciente agudo*, or “care for patients with acute dependence on psychoactive substances”), 127 (*internación hospitalaria consumidor de SPA*, or “hospitalization for users of psychoactive substances”), and 128 (*internación parcial consumidor de SPA*, or “partial hospitalization for users of psychoactive substances”).
- 10** For the case of palliative care, many of the registered providers are dedicated exclusively to pain management (e.g., “pain clinics”) but do not offer comprehensive palliative care services.
- 11** Within secretariats of health, the staff member in charge of mental health is usually the one responsible for substance use disorders; however, we found that the secretariats have not yet clearly defined which staff member is responsible for the issue of palliative care.

In addition, the number of interviews with patients and PWUD was limited due to the particular circumstances of these individuals. For one, end-of-life patients were undergoing treatment or were in the final moments of their lives, with loved ones providing the necessary care, which limited the possibility of our being able to speak with them; indeed, conducting interviews with patients at this moment in their lives would have been disrespectful of their personal journeys. Second, with regard to PWUD, the possibilities of speaking with these individuals were usually limited to times when they were undergoing inpatient treatment. For PWUD who were living on the street or were actively using drugs, it was difficult to find a space in which to talk and a time when they were not under the influence of these substances or uncomfortably craving their next dose.

In total, we conducted 103 structured interviews drawing on questions of both an informative and a descriptive nature. The interviews fell largely into two groups: interviews with health authorities who offered a general overview of the situation in their respective city, and interviews with physicians and patients who offered insights into barriers and their impacts. For every interview, we obtained the individual's verbal or written consent to be a part of this study. Whenever we quote interviewees throughout the book, we have changed their names to protect their privacy.

In addition, in order to better understand the dynamics of heroin use in each city, we reached out to representatives of needle-exchange programs¹²—programs that help reduce the risk of transmissible infections among heroin users—who allowed us to accompany them on their outings in the streets or to be present at delivery stations during key hours. We did this in each city except Santander de Quilichao. These street rounds allowed us to meet people who use heroin and better understand their living situations, expectations, and needs.

In cities such as Cali, where the provision of palliative care services is relatively developed, we were able to accompany health care workers on their home visits and participate in workshops for caregivers. These settings allowed us to witness the challenges involved in palliative care, the importance of home-based palliative care, the possibilities that palliative

12 These programs are run by civil society organizations, often with government funding.

care offers to patients and their families, and the valuable support provided by social workers and psychologists during these last moments of life.

After conducting these visits, it became evident that we needed more qualitative and quantitative information on the dimension of service provision in each city—or lack thereof, particularly among the EAPBs that did not respond to our requests for interviews. To this end, we submitted 144 *derechos de petición* (petitions sent within the framework of Colombia's right to access public information, similar to requests submitted under the US Freedom of Information Act) to EAPBs, IPSs, and Regional Narcotics Funds in each city, requesting information about their patient care models, the number of patients attended to, their purchase and sale of opioid medicines, and other issues that would allow us to properly map, expand on, and corroborate the information collected during the fieldwork stage. Of the 144 petitions sent, 53 received a response, 30 were undeliverable (i.e., “return to sender”), and 61 were ignored.

Considering this low response rate, especially among the EAPBs, we decided to resend our petitions to these entities. In this second round, we sent approximately 40 requests; of the few entities that responded, all refused to provide this information on the grounds of professional and trade secrecy. It is worth highlighting that our petitions were of a general nature, as we requested aggregated and anonymized data. In response to most of these denials, we submitted requests for reconsideration, which were once again ignored or answered with yet another refusal. Given that most of the entities to which we sent petitions are private, we can presume that they do not consider themselves legally obligated to provide a response.

To systematize the information collected during the fieldwork phase, we designed a form that recorded the most important information from each interview according to the type of actor interviewed. In general, our organization of this information took into account the type of care in question, the barriers to accessing treatment, the accreditation process for IPSs, EAPBs' relationship with other actors, and the availability of opioid medicines and barriers to accessing them. For the information on palliative care patients and PWUD, we recorded individuals' diagnoses, histories of drug consumption, and support networks. Once we systematized this information from the interviews, we coded and analyzed it using N-Vivo, a software for interpreting qualitative data. We coded each one of the 103 interviews according to the following information hubs: (i) type of actor (EAPB, IPS, Regional Narcotics Fund, patient, PWUD,

community worker, professional association, or departmental and municipal secretariat of health); (ii) type of treatment (palliative care or drug dependence); (iii) city (Armenia, Pereira, Cali, Santander de Quilichao, or Cúcuta); treatment plan; (v) barriers to accessing treatment; (vi) availability of opioids; (vii) barriers to accessing opioids; and (viii) recommendations. Once we coded the data according to these hubs, we generated reports consolidating these issue areas in order to have a panoramic view of the issues in each city. In addition, we systematized the responses to our petitions—largely from IPSs—in Access.¹³

Lastly, our study underwent three internal and external review processes. First, researchers at Dejusticia provided feedback on the document as part of an open-discussion seminar in which researchers shared their views both verbally and in writing. Second, the study was reviewed by four experts—two in palliative care and two in drug dependence treatment—at the national and local levels. The two experts in drug dependence and treatment were Ana María Cano¹⁴ and Inés Elvira Mejía,¹⁵ practitioners of psychosocial care for people suffering from substance use disorders. The two experts in palliative care and opioid use were Paola Marcela Ruiz¹⁶ and Marta Ximena León.¹⁷ Third, we shared our research findings with local authorities, health practitioners, professional associations, and community workers, all of whom work with these two populations in the selected cities, during two workshops held in Cali and Pereira

13 We systematized this data using a form in Access that, in turn, contained several subforms that we constructed with fields to capture information from every *derecho de petición*. We then entered the systematized information into an Excel database that allowed us to produce complete and comparable information.

14 Psychiatrist with expertise in care for people with psychoactive substance use disorders; former scientific director of Filandia Mental Hospital (Quindío); professor of psychiatry at University of Quindío's School of Medicine.

15 Psychologist with postgraduate degree in drug and alcohol policy and interventions and a master's degree in social policy; consultant with national and international organizations on issues of drug policy reform, HIV/AIDS, sexual and reproductive health, and harm reduction.

16 Geriatric physician with a medical degree from the University of Caldas, a postgraduate degree in palliative care from the Instituto Pallium (Argentina), and a master's degree in palliative care from the University of Valladolid (Spain); currently chief of geriatrics and palliative care at Caldas Hospital and president of the Palliative Care Association of Colombia.

17 Anesthesiologist specializing in pain and palliative care; fellow in pain and policy at the University of Wisconsin (United States); chief of the Anesthesiology, Pain and Palliative Care Department at the University of La Sabana.

in November 2018. Most of the people who participated in these workshops were people we interviewed during our fieldwork.

To disseminate our research findings, we organized two day-long work sessions based on human-centered design, an approach that promotes creative and collaborative processes for the design of public policies based on the needs of users. The sessions involved a series of straightforward activities aimed at helping various actors within the health system understand the daily barriers faced by people in need of opioid medicines and generated plausible, feasible, and desirable solutions for overcoming them. At the end of each workday, participants converted their ideas into concrete action plans with goals, courses of action, resources, actors, and beneficiaries. Some of the solutions generated during these sessions were incorporated into our final recommendations, which are presented in chapter 4. This sharing process proved an ideal setting for conversing with those who attend to the needs of these populations on a daily basis, and their feedback was valuable for adjusting certain aspects of our recommendations in order to ensure that they possess real potential to generate change.

The Book's Structure and Some Conceptual Clarifications

This book consists of four chapters that explore opium, its derivatives, and their effects; the Colombian health system; the relationship between the international drug control system and the enjoyment of human rights; the lives of people who use drugs and seek treatment for their dependence; and the quest for pain relief as death nears.

In chapter one, we describe the effects of opioids on the human body in order to highlight their medical importance for our two focus populations. We also explore the state's efforts to ensure the availability and accessibility of opioids, explaining the workings of the Colombian health system and the regulations that govern controlled substances in the country. In chapter two, we focus on what we call "lives on the margins": the situation of people addicted to heroin. Here, we discuss the national and regional panorama as it relates to heroin use, its impacts on health, and the barriers to accessing methadone treatment. Chapter three addresses palliative care services, the implementation of Law 1733 (which incorporates these services into the country's Health Benefits Plan), the recent growth

of palliative care in Colombia, the need for this kind of care, and the barriers that prevent patients from accessing palliative care and opioids for pain relief. We conclude the book with a chapter that offers conclusions and recommendations, with an eye toward generating solutions to ensure the effective enjoyment of the right to health among the populations for whom we wrote this book.

A multitude of terms are used to describe dependence on psychoactive substances. Some of them—addiction, habit, abuse—have negative connotations that propagate stigma and should be avoided (Scholten 2015). In this way, language is a minefield, meaning that a given word may serve not only as a psychiatric judgment but also as a tool to deepen or reproduce certain types of discrimination. Throughout the book, we use the phrase “substance use disorder,” which is more neutral. The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* characterizes such disorders as being measured along a continuum from mild to severe (American Psychiatric Association 2013).

The word “addiction” has Latin roots that mean “enslaved by” or “bound to” (Szalavitz 2016, 23). The word “abuse,” also used to refer to the problematic use of drugs, is considered demeaning and derogatory, for it is often used to describe actions such as “sexual abuse,” “child abuse,” and other behaviors of a different nature and much more severe than problematic drug use (ibid., 30–31). The word “dependence” is also pathologized. As Maia Szalavitz explains, the Alcoholics Anonymous movement has been using this term since the 1980s, especially to describe toxic and negative romantic relationships, deeming such relationships to be “codependent.” For example, obsessive relationships where the spouse of a person with drug dependence tries to help that person repeatedly without success are described as pathological relationships. The term “dependence” has therefore begun to connote weakness (ibid., 152).

In general, we should take care to ensure that the words we use to define and describe these situations put the person first. This is in line with the World Health Organization’s recommendation that the terminology used in drug control laws and policies be clear and unambiguous in order to avoid confusion between the medical and nonmedical uses of controlled substances (World Health Organization 2011, 28; Scholten 2015).

In this book, we wish to affirm the need to restore empathy toward those who have developed a problematic reliance on drugs. In the words of Maté, it is easy to be moved by the suffering of others—by their starvation,

illness, or pain—but it is very difficult to see the child in an adult who uses drugs and who once suffered hunger, pain, or trauma. Those living on the fringes whom we see as “junkies” are not creatures from another planet: they are human beings like us, on another end of the continuum, and as a society we cannot understand one another without first seeing our own shadows (Maté 2010, 2, 37).

Moreover, we wish to recognize and exalt the bravery involved in acknowledging that we humans are mortal. Palliative care allows us to stop seeing death as an enemy. As Atul Gawande teaches us, death has superior forces and eventually wins, and we cause greater damage when we try to act like a warrior who fights until the point of total annihilation. The job of medicine should not be simply to preserve life for life’s sake—rather, it should also involve enabling and facilitating the best quality of life at each step of the way, in accordance with the wishes of the person who is approaching the end (Gawande 2014, 169, 287). This book is an invitation to broaden our way of thinking about drug dependence and the end of life.

CHAPTER 1

THE STATE'S RESPONSE TO PAIN: CHALLENGES TO ENSURING THE AVAILABILITY OF OPIOID MEDICINES

To talk about the end of life, treatment for heroin use disorder, and the need for respect for human dignity in these processes, we must first understand pain and the ways that pain relief works, as well as the actions the state must take as guarantor of human rights, especially the right to health and the right not to be subjected to cruel, inhuman, or degrading treatment. The obligations of the Colombian state pose a conundrum, since the international drug control system calls for controls on opioids that, in the context of a structurally deficient health system, impede pain relief for patients who need it.

Pain can have consequences beyond the physical. When an individual experiences severe or chronic pain—a common occurrence among patients facing the end of life due to a chronic or terminal illness—that person may experience what is known as “total pain.” This palliative care concept was coined during the hospice movement by Cicely Saunders, who sought to offer a comprehensive description of pain that includes not only a physical component but also psychological, emotional, spiritual, cognitive, and social ones (Pallipedia 2019). Naming and acknowledging pain in this way calls for a similarly comprehensive approach to its mitigation, which implies recognizing the range of the patient’s needs and finding ways to provide the best quality of life possible (López-Sánchez and Rivera-Largacha 2018, 341). While this concept originates from the practice of palliative care, it is also applicable to the suffering experienced by people who depend on heroin, which we will address in greater detail in chapter two. Even when a patient is able to take opioid medicines to alleviate physical pain, the barriers to accessing them can negatively affect

each of the other spheres of total pain, causing severe suffering for patients and their families.

Similarly, drug withdrawal symptoms can be both physical and psychological. People experiencing withdrawal can suffer from nausea, vomiting, extreme sweating, extreme cold, insomnia, anxiety, tremors, and weakness, to name a few symptoms. According to those who have lived through the rough days of the *mono*, *maluquera*, or *torquis*,¹⁸ there is also emotional pain upon the sense of losing one of the only things that has made life bearable and psychological pain upon anticipating a period of transformation. When individuals begin detoxification, they revisit their personal histories of pain, as they must face quitting drugs, leaving behind something that has given them relief and tranquility (Szalavitz 2016, 33). Life after detoxification, then, is not just a physical challenge but an emotional and mental one. Methadone can alleviate the physical symptoms, but much more is needed to be able to overcome the loss and distress of the emotional and mental symptoms of quitting heroin.

In both cases, part of the solution for physical pain lies in medicines derived from opium poppy or synthetic compounds that mimic its chemical composition. Opioids have proven to be effective analgesics for specific symptoms. When they enter the body, they adhere to opioid receptors, which are responsible for generating feelings of pleasure, gratification, and pain. Their effectiveness derives from their effect on the opioid system in the brain and from simulating the effect of endorphins—which make us feel good—so that the body no longer feels pain (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33). But in addition to their impact on our central nervous system, opioids affect our gastrointestinal system and spinal cord (Brailowsky 2002, 134). One of the fundamental effects of opioids is the way we *experience* pain, since they act on receptors in our body that alleviate the uncomfortable sensation of pain itself. It's not that the individual doesn't feel pain—but rather that the person no longer perceives it as such.

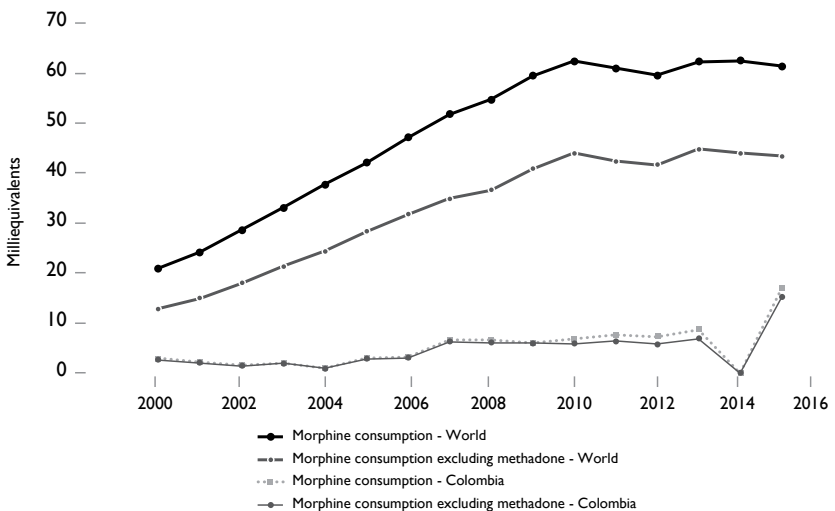
Chemically, the human body is constantly producing opioids: these opioids are endorphins, which make us feel good and which bind to the same receptors as opioid medicines. When endorphins are released in the body, they allow us to tolerate greater levels of pain. Opioid medicines essentially simulate the release of endorphins. There is an extensive catalogue

18 Three slang words commonly used to describe withdrawal symptoms.

of opioids for relieving pain: weak opioids such as codeine and tramadol, and strong opioids such as morphine, hydromorphone, methadone, fentanyl, oxycodone, tapentadol, and buprenorphine, among others.¹⁹

Thus, a country’s consumption of opioid medicines is a rough indicator of the extent to which its citizens are able to effectively manage pain. Although Colombia’s morphine consumption has grown significantly in recent years—from 3 mg per capita in 2005 to 17 mg per capita in 2015, according to the most recent National Opioid Survey (Observatorio Colombiano de Cuidados Paliativos 2018)—this consumption is concentrated in large and medium-sized cities, demonstrating marked subnational disparities in the management of pain. As shown in the following graphic, consumption has risen steadily over the years, but it remains far from the global average of 61.49 mg per capita.

Figure 1
Opioid consumption in Colombia and the world



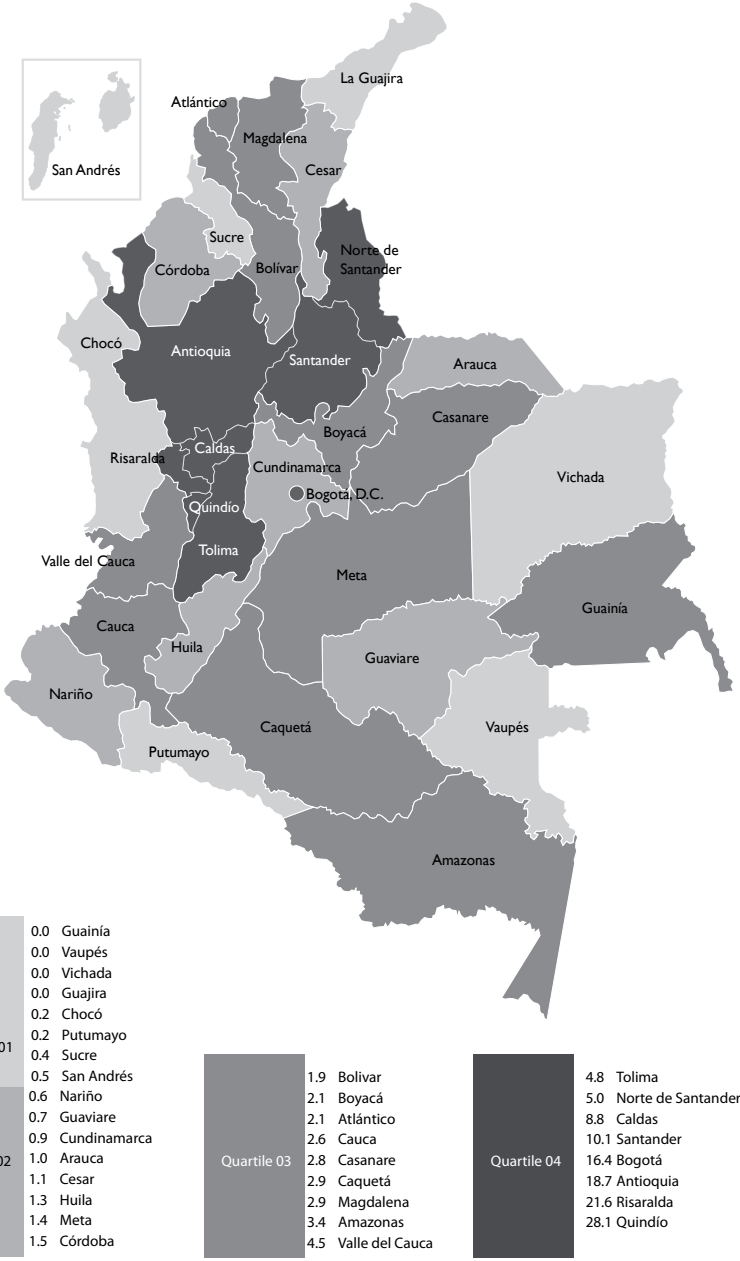
* The lack of information for Colombia for 2014 is due to the fact that even though the Colombian government reported its data before the International Narcotics Control Board, this information was not officially recorded.

SOURCE: Prepared by the authors using data from the Pain and Policy Studies Group

¹⁹ See this book’s annex for a list of the opioids that are available in Colombia.

Map 1

Opioid consumption by department



SOURCE: Colombian Observatory for Palliative Care. <http://occp.com.co/region/mapa-opioides/>

As shown in the map, opioid use is conspicuous in departments such as Quindío, Risaralda, Antioquia, and Santander. However, in sixteen of Colombia's thirty-two departments, opioid consumption is less than 2 mg per capita, suggesting inadequate pain management among a significant portion of the country's population.

To explore the state's response to pain and to protection of the right to health, this chapter is divided into four parts. In the first part, we discuss the crossroads in which opioids find themselves as a result of their dual status as an essential medicine according to international health standards and a controlled substance according to the international drug control system. In the second part, we describe the role that opioids play in palliative care, and in the third part, we describe their role within the framework of treatment for heroin dependence. In the fourth and last part, we explore the mechanisms adopted by the Colombian state to ensure access to and the availability of opioid medicines, as well as the barriers standing in the way of this goal.

Opioid Medicines: Straddling the Divide between Essential and Controlled

Physical pain and emotional pain are processed in the same part of the brain, in an area with abundant opioid receptors (Szalavitz 2016, 34). Physical pain caused, for example, by metastatic cancer can, to a certain extent, be comparable to the emotional pain caused by approaching death or by the attempt to overcome heroin dependence, given that they are transmitted from the same place in the brain and with the same receptors. They are experiences of *total pain*.

Furthermore, the way we feel pain is affected by the meaning that we ascribe to it, whether this is based on previous experiences or the context in which the pain occurs. Studies have shown that pain is felt most acutely when fear and worry are present. It is plausible that in both situations—being a patient at the end of life or a person who uses heroin—fear and worry are a constant, making the pain more intense. All of this reinforces the need to ensure that opioid medicines are a key component of health care for these populations, and it supports the argument that the failure to ensure their availability and access contravene human rights, including the right to health and the right to be free from cruel, inhuman, and degrading treatment.

These substances are classified as prohibited substances in the Single Convention on Narcotic Drugs of 1961, which Colombia has ratified.²⁰ Opium poppy and its derivatives are among the plants prohibited by this convention;²¹ they appear in schedule 1, which lists the substances subject to the strictest level of control. At the same time, the convention acknowledges the medical and scientific uses of these substances and requires states parties to have structures in place to manage the cultivation, manufacture, export, and import of opium poppy and its derivatives. To this end, Colombia has established the National Narcotics Fund, whose structure, functions, and challenges will be explored later.

Opioids, in addition to being controlled, are essential. Many of the medicines derived from opium have been included in the World Health Organization's list of essential medicines, which has a section devoted to opioid analgesics (World Health Organization 2017, 2).²² The latest edition of this list includes several forms of morphine, and its complementary list includes methadone.²³

The international drug control system has created a strange paradox, for while the preamble of the 1961 drug convention refers to the welfare of humankind and the need to ensure the availability of controlled substances for medical and scientific purposes, the reality is that excessive control measures have made it impossible for many people to access opioids when in need. According to the United Nations Office on Drugs and Crime (2018), worldwide only one in six people with drug use disorders is receiving treatment. In addition, an estimated five billion people are living in countries with little or no access to pain medicines (European Society for Medical Oncology n.d.).

20 Ratified via Law 13 of 1974.

21 The Single Convention on Narcotic Drugs of 1961 is an international treaty that outlines control measures for certain psychoactive substances, including marijuana, cocaine, and opioids.

22 See annex.

23 It is important to point out that naloxone—a medication used to counter the effects of an opioid overdose—is available only in hospital settings in Colombia, even though it is not a controlled substance. The human brain stem, the area of the body that controls processes such as breathing and blood pressure, has many opioid receptors, which is why an opioid overdose carries a high risk of death. In such cases of overdose, naloxone is essential for reversing the drugs' effects (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33).

These international standards are enforced by states at the domestic level by controlling and suppressing each phase of the psychotropic drug economy, from production to consumption. This dynamic has led to the phenomenon of “conflicting obligations,” in which states’ efforts to comply with their treaty obligations on drug control lead to noncompliance with their international human rights obligations (Uprimny Yepes, Guzmán-Rodríguez, and Parra Norato forthcoming). Multiple international human rights bodies have called attention to this predicament. States’ failure to provide essential opioid medicines via their health systems has been deemed a human rights violation by the United Nations Special Rapporteur on the Right to Health and the United Nations Special Rapporteur on Torture.

In recent years, the drug control system itself has acknowledged the collateral effects of the restricted availability of these substances for medical uses, and this concern has resonated at the multilateral level. In the lead-up to the 2016 UNGASS, recognizing the pivotal moment represented by this event, a group of United Nations experts and mechanisms sent a joint letter to the president of the United Nations General Assembly and to the United Office on Drugs and Crime to call for the inclusion of human rights standards in international drug control policies and to encourage this policy framework to emphasize improved access to controlled medicines and evidence-based treatment for drug dependence. And in effect, the outcome document from UNGASS 2016 took into account these two issues by including relevant operational recommendations for states (see United Nations 2016).

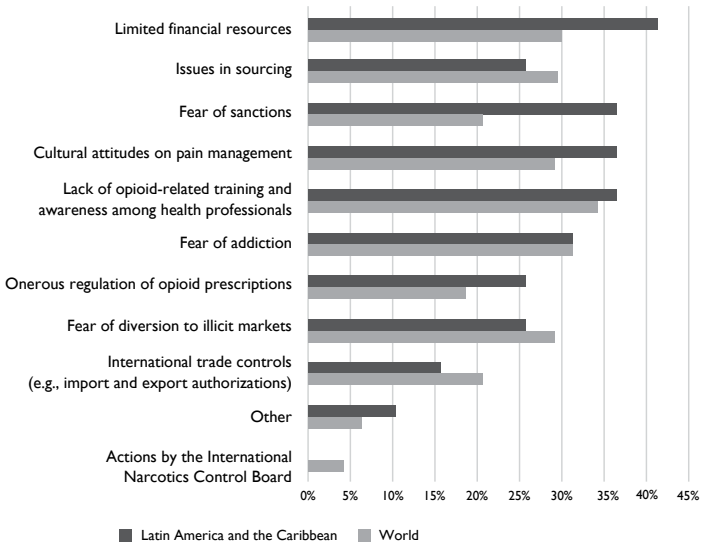
Despite global discussions on the importance of ensuring the availability and accessibility of these medicines for those who need them, the reality is that people continue to suffer the consequences of these medicines’ controlled status. The restriction of opioid medicines has serious impacts that vary depending on the country. The Lancet Commission on Palliative Care and Pain Relief²⁴ has deemed this crisis the “access abyss,” whereby the world’s poorest suffer the most. According to the commission, of the 298.5 metric tons of morphine-equivalent opioids distributed annually across the globe, just 0.1 metric ton reaches low-income

24 *The Lancet* is a British medical journal that has various technical commissions. The commission we refer to in this book is the Lancet Commission on Palliative Care and Pain Relief. See <https://www.thelancet.com/commissions/palliative-care>.

countries (Knaul et al. 2018, 1). While countries spend US\$100 billion on enforcing the global prohibition of drug use, a mere US\$145 million would be needed to close this opioid access abyss for low- and middle-income countries (ibid., 4). At the personal level, the lack of pain relief or the inability to manage withdrawal symptoms to overcome drug dependence can negatively affect an individual’s quality of life, personal achievements, relationships, and ability to make a living.

The controlled nature of opioid medicines also affects the work of health professionals, whose actions often translate into additional barriers for patients. A 2016 study by Stefano Berterame et al. identified the key factors inhibiting access to and the availability of opioids and classified them into ten categories. The study’s authors surveyed national authorities in 214 countries on the impediments to opioid use in their countries. As shown in the following graph, limited financial resources were reported as the main barrier in nearly half of the Latin American and Caribbean countries surveyed, followed by a lack of training and awareness among medical professionals, cultural attitudes around pain, and fear of sanctions and addiction (in other words, opiophobia).

Figure 2
Factors impeding opioid use in Latin America and the Caribbean



SOURCE: Prepared by the authors with data from Berterame et al. (2016, 10)

The Lancet Commission on Palliative Care and Pain Relief defines opiophobia as “the prejudice and misinformation surrounding the appropriate medical use of opioids in the context of a balanced approach that reduces risks of non-medical use” (Knaul et al. 2018, 8). Other authors have defined it as “a fear shared by ‘regulatory agencies, healthcare professionals, [patients] experiencing acute and chronic pain, and their families,’ despite the fact that ‘studies confirm that [opioid] abuse and addiction are rare among chronic pain clients’” (*MD Magazine* 2011). This highlights the fact that a significant portion of existing barriers could be minimized through less onerous regulations and better training for health professionals (Berterame et al. 2016).

In this sense, states’ “conflicting obligations” concerning the control of, availability of, and access to opioid medicines has a direct impact on the fulfilment of the right to health and the right not to be subjected to cruel, inhuman, or degrading treatment, as we will see in the next section.

Pain Relief as a Guarantee of the Right to Health and the Right to Be Free from Cruel, Inhuman, and Degrading Treatment

The right to health is enshrined in various international human rights instruments. The Universal Declaration of Human Rights recognizes everyone’s right to an adequate standard of living, including medical care (art. 25). In addition, the International Covenant on Economic, Social and Cultural Rights establishes the right to enjoy the highest attainable standard of physical and mental health (art. 12).

At the regional level, the American Declaration on the Rights and Duties of Man enshrines everyone’s right to the preservation of their health (art. 11), and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) recognizes the right to health according to the same terms as in the International Covenant on Economic, Social and Cultural Rights, requiring states to adopt certain measures to ensure this right, including primary health care, the extension of health care to everyone, and the prevention and treatment of endemic, occupational, and other diseases (art. 12).

The right to health as enshrined in article 12 of the International Covenant on Economic, Social and Cultural Rights is a fundamental human right that consists not of “the right to be healthy” but of the *right to the highest attainable standard of health*, which entails rights and freedoms

related to decisions about one's body, as well as guarantees of the highest possible level of mental well-being, which requires being free from pain. Further, as indicated in General Comment 14 on the right to health—issued by the Committee on Economic, Social and Cultural Rights in 2000—access to “essential medicines” as defined by the World Health Organization is a key element of the right to health and a core obligation of states (United Nations Committee on Economic, Social and Cultural Rights 2000, paras. 12, 43). Moreover, the committee notes that states are obligated to respect the right to health, including through the provision of palliative health services (*ibid.*, para. 34).

Thus, General Comment 14 recognizes that “health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity” (*ibid.*, para. 1). Furthermore, it explains that the right to health contains a series of essential elements that states must guarantee in order to allow their populations to attain the highest level of physical and mental health. Among these elements are the following:

Accessibility: This means that health services must be accessible to everyone without discrimination. To this end, health care providers must ensure a differentiated approach, guarantee the physical accessibility and affordability of their services, and ensure the accessibility of information for patients.

Acceptability: Health facilities, goods, and services must be respectful of the different cultures of patients.

Quality: Health care providers must have “skilled medical personnel, *scientifically approved and unexpired drugs* and hospital equipment, safe and potable water, and adequate sanitation” (*ibid.*, para. 12; emphasis added).

In a 2016 report on the complementarities between the right to health and the 2030 Agenda for Sustainable Development, the Special Rapporteur on the Right to Health pointed out that legal frameworks can exacerbate inequality and discrimination against certain populations, which can have the effect of excluding them from access to health services or making them afraid to seek such services. The Special Rapporteur placed particular attention on the situation of people who use drugs and people suffering from pain at the end of life:

[L]aws criminalizing drug use may drive people who use drugs from life-saving harm reduction services ... Restrictive and punitive drug policies can deprive people suffering from pain of their right to palliative care. (Pūras 2016, para. 46)

In 2010, the Special Rapporteur on the Right to Health noted that the emphasis on non-evidence-based treatment models—which are often forced on patients—causes them to suffer through unmedicated withdrawal and that this problematic situation is further reinforced by regulatory barriers to accessing controlled substances (Grover 2010, para. 36), as we will discuss in chapter two on the experiences of people who use heroin.

Meanwhile, the Special Rapporteur on Torture, in a 2013 report, elaborated on the framework for protection against torture and ill-treatment in health care settings, stating that “when the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment” (Méndez 2013, para. 55). Thus, the Special Rapporteur considers the following actions to constitute violations of the right not to be subjected to cruel, inhuman, or degrading treatment: (i) the denial of medication to relieve the suffering caused by withdrawal symptoms in the case of people who use drugs (*ibid.*, paras. 41, 44) and (ii) the denial of treatment for moderate to severe pain as a result of states’ failure to establish mechanisms to ensure access to opioids (*ibid.*, para. 53).²⁵ The Special Rapporteur concludes that because these acts of omission inflict severe suffering, they constitute a human rights violation and should be remedied by ensuring the availability and accessibility of medicines included in the World Health Organization’s list of

25 This paragraph of the Special Rapporteur’s report reads: “Although relatively inexpensive and highly effective medications such as morphine and other narcotic drugs have proven essential ‘for the relief of pain and suffering’, these types of medications are virtually unavailable in more than 150 countries. Obstacles that unnecessarily impede access to morphine and adversely affect its availability include overly restrictive drug control regulations and, more frequently, misinterpretation of otherwise appropriate regulations; deficiency in drug supply management; inadequate infrastructure; lack of prioritization of palliative care; ingrained prejudices about using opioids for medical purposes; and the absence of pain management policies or guidelines for practitioners.”

essential medicines, which is furthermore a legal obligation under the 1961 Single Convention on Narcotic Drugs (ibid., paras. 54, 55).

Opioids in Palliative Care

When a person faces the end of life due to a chronic or degenerative illness, pain is one of the main concerns of both the patient and his or her family. As human beings, even though we are conscious of our mortality, we often dodge the reality of death; and as a society, we are far from embracing the end of life with awareness and honesty. But even while acknowledging and speaking about death might be difficult, progress in palliative care in recent decades has made this final step of life much easier.

This section focuses on pain management at the end of life from the perspective of health professionals who have dedicated their careers to helping patients in their final stages secure the best quality of life possible. The discussion that follows is based on our interviews with experts in the field, as well as a review of specialized literature.

According to the International Association for Hospice and Palliative Care, palliative care is “the active holistic care of individuals across all ages with *serious health-related suffering* due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers” (International Association for Hospice and Palliative Care 2019a, emphasis added). According to this framework, states should ensure access to opioid medicines, which are a fundamental tool for the relief and management of pain.

Serious health-related suffering is defined as suffering that cannot be relieved without professional intervention and that compromises a person’s social, physical, or emotional functioning.²⁶ Worldwide, severe health-related suffering affects an estimated sixty-one million people, 80% of whom live in low- and middle-income settings (Knaul et al. 2018, 2). For 2015, 45% of deaths worldwide involved severe suffering according to the standard established by the Lancet Commission on Palliative Care and Pain Relief. This is equivalent to 25.5 million people.

26 Across the globe, palliative care has been provided largely for cancer and HIV patients in their final stage of life, but according to the standards outlined by the Lancet Commission on Palliative Care and Pain Relief, there are other conditions that also involve serious health-related suffering, namely cerebrovascular disease, dementia, lung disease, liver disease, non-ischemic heart disease, and injury (Knaul et al. 2018, 3).

According to surveys carried out among terminally ill patients, what matters most during this time is not prolonging life but avoiding suffering, strengthening relationships with loved ones, being mentally aware, and not being a burden on others (Gawande 2014, 155). But heroic measures, insistence on curative treatment, and overmedicalization at the end of life have prevented these priorities from being at the center of health care. Such behaviors are termed “medical futility” in end-of-life care, as they do not improve the patient’s health or affect prognosis or outcome—but they do generate a high degree of suffering while also delaying the possibility of receiving palliative care.

There is a fundamental difference between a cure and a treatment. While many illnesses experienced by individuals seeking palliative care cannot be cured, they can be treated, and it is here that palliative care becomes essential. Palliative care seeks not to “save” a life but to alleviate the symptoms that most dramatically affect the quality of life of the patient and his or her loved ones. One of the symptoms that causes the most unease, both physically and mentally, is pain, especially the severe pain that often accompanies the final phase of illnesses such as cancer.

The question that should thus precede the provision of palliative care is this: When should doctors provide curative care, and when should they reorient their efforts toward managing symptoms? This question has not only ethical dimensions but also financial ones, considering that the health system’s limited resources necessitate priority setting in expenditures. In the United States, a study from 2010 revealed that 25% of all Medicare²⁷ spending was going to 5% of patients in their final year of life and that most of this spending was of little apparent benefit during the patients’ last few months (Gawande 2014, 153).

But the truth is that in most cases, the question whether to apply a curative approach is not addressed by health practitioners, patients, or patients’ families. The conversation is never held, and so a patient’s arrival at the end of life tends to be overrun by harried emergency room visits, without a clear sense of what is happening and what comes next. The absence of this important conversation has dramatic consequences: according to a 2008 study published by the Coping with Cancer project in the United States, patients who were submitted to heroic measures—such as being put on a mechanical ventilator or given electrical defibrillation—experienced

27 Medicare is a public health insurance program in the United States.

a worse quality of life during their final week than those who were not subject to such interventions. Further, their loved ones were also affected: six months after the patient's death, their caregivers were three times more likely to suffer serious depression (*ibid.*, 155).

To alleviate suffering—of which pain is a part—opioids play a key role. According to the visual analogue scale for pain, a medical measurement tool, a patient's pain is classified as mild, moderate, or severe. Opioids are given in accordance with the level and type of the patient's pain,²⁸ and a professional evaluation of the pain scale allows the treating physician to decide what dose to prescribe and to continue monitoring in order to determine whether the pain is being effectively managed. Due to the general fear of opioids—whether concerning adverse reactions or the cultural connection that exists between opioids and death—emergency room services often administer very low doses of morphine that are sub-optimal for pain management. This fear is reinforced by the perceptions of family and loved ones, who often think that when the patient receives morphine, it's because “this is very serious, they're going to die, and this is all that's left.”²⁹

The Lancet Commission attributes this neglect to the medical focus on extending life and productivity (two major drivers of policy and investment), opiophobia,³⁰ low levels of patient advocacy and mobilization, and the focus on controlling opioid substances instead of ensuring their availability, among others (Knaul et al. 2018, 1). This medicalization of death has contributed to a type of medical practice in which the goal is to save lives, not to spend time thinking about when efforts should be redirected toward palliative care. Further, the failure to alleviate physical pain has consequences that go beyond the physical, as the Special Rapporteur on the Right to Health has pointed out:

28 It is worth noting that severe pain is not always the result of cancer or the end of life; rather, its presence is determined by an evaluation of the patient according to the pain scale.

29 Interview with Marta Ximena León, 2017.

30 In its report, the commission defines opiophobia as “prejudice and misinformation surrounding the appropriate medical use of opioids in the context of a balanced approach that reduces risks of non-medical use” (Knaul et al. 2018, 8). In another article, opiophobia is defined as “a fear shared by ‘regulatory agencies, healthcare professionals, clients experiencing acute and chronic pain, and their families,’ despite the fact that ‘studies confirm that [opioid] abuse and addiction are rare among chronic pain clients’” (*MD Magazine* 2011).

[P]eople experiencing chronic pain are four times more likely to suffer from depression or anxiety. Patients suffering from severe to moderate pain, where palliative care essentially is unavailable, said they would prefer to die than continue living with untreated, severe pain. (Grover 2010, para. 43)

Morphine—as with most opioids—has a half-life of two to five hours, except for extended-release formulas, which last for twelve hours (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33). In either case, a patient experiencing severe and constant pain requires permanent pain management. Depending on the route of administration, different concentrations and dosing intervals are needed; and to make this call, the treating physician should have proper training. However, this knowledge is limited in practice given that such training in Colombian medical schools is basic at best and altogether absent in other disciplines, such as nursing.

The administration routes for opioids are a crucial aspect of palliative care, given that many factors at the end of a patient’s life can converge in order to make it difficult for the patient to swallow (the oral route) or to receive an injection (the intravenous route).³¹ For every type of patient, then, there is an appropriate opioid form, which makes it imperative that medical associations maintain constant dialogue with drug regulatory authorities in order to determine which routes of administration should be available in the country.

As with many medicines, opioids have side effects that should be explained to patients and monitored, such as nausea, drowsiness, and vomiting; these effects are manageable when opioids are begun at low doses and then gradually increased according to the patient’s reaction. It is worth noting that widespread overestimation of opioids’ possible side effects—which stems from health practitioners’ lack of training on the issue—has led physicians to hesitate to prescribe or administer opioids and patients to resist receiving the drugs.

Furthermore, the barriers to accessing opioids that we will explore below are rooted in a drug control system that seems based on the fear that opioids’ availability will trigger a wave of addiction. However, a review of

31 The oral route of opioid administration is the least effective route (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33).

the available scientific evidence makes clear that the control system as it concerns opioids is actually excessive, since the risk of developing a dependence on controlled substances—in the hands of trained professionals and with appropriate monitoring—is much less than the fear of prescribing them. A meta-analysis from 2006 reviewed international research covering more than 6,000 patients who had received opioids for pain that was not cancerous in origin, concluding that there was no significant risk of dependence (Maté 2010, 141).

Alleviating pain at the end of life gives individuals the capacity to make autonomous decisions regarding the process. When relatives and friends ask, “Is my loved one dying?,” the response of health professionals is often influenced by the use of medical technologies. We remain alive, our bodies hooked to machines that allow us to breathe, but without the possibility of making decisions about our end (Gawande 2014, 158).

Thus, having information is indispensable for being able to exercise autonomous decision making at the end of life. Patients must be able to understand their prognosis and the possible deterioration that might await them. However, the information asymmetry between doctors and patients means that many elements of this process are not communicated in time or are poorly managed by the physician. In 2000, sociologist Nicholas Christakis asked the physicians of nearly 500 terminally ill patients to estimate how much time these patients had left before dying. He then followed this group of patients and found that 63% of the physicians had overestimated their patients’ survival time, and not by a little: physicians’ estimates, on average, granted patients 530% more time than they actually ended up living (*ibid.*, 167).

Putting palliative care within the reach of all patients who require it necessitates a radical change in the way modern medicine operates. In today’s medicine, the goal is to prolong life, which is often done by reducing the quality of life during a certain period in order to stretch it out, but in conditions that are undignified. In palliative care, these priorities are inverted: health workers’ efforts focus on securing the best quality of life possible for the patient, which is not always synonymous with living longer. In other words, in palliative care—provided that there has been a sustained relationship among the medical team, the patient, and the patient’s family—end-of-life decisions are issues that have been discussed and that patients are prepared to handle.

Heroin Dependence and Treatment with Opioids

Medicine-assisted treatment is used for heroin use disorder, but to be able to understand how it works, we must first comprehend what it means to be dependent on psychoactive drugs. This is a problem toward which societies seem to prefer to turn a blind eye, and practitioners in this field whom we interviewed for this book showed us their conscious decision to seek solutions for forgotten populations, always respecting their dignity and autonomy. In this section, we will explore how psychoactive substance use disorders work and how they are experienced by individuals, based on our interviews with experts and a review of the specialized literature.

There is a heated debate around definitions concerning the problematic use of psychoactive substances, given that drug consumption has become highly politicized and moralized as a result of prohibition. In particular, there is disagreement over whether psychoactive substance use disorders are a disease or a psychosocial condition.³² If they are treated as a disease, treatment tends to be overmedicalized and neglectful of associated psychosocial factors; meanwhile, not recognizing these disorders as a disease runs the risk of ignoring the need for medicines as part of treatment. This morally, politically, and socially motivated debate aside, it is important to emphasize that psychoactive substance use disorders are a complex phenomenon with multiple causes and dimensions. A range of explanatory models exist, each one calling for a particular approach to the problem. Drug use has numerous causes, consequences, and social components, as it involves the interaction between an individual—with unique social and biological traits—and substances that affect brain processes. The assortment of explanatory models is thus a reflection of the complex interactions among these factors.

For the purposes of our research, we adhere to the definition provided in the tenth revision of the *International Statistical Classification of Diseases and Related Health Problems* (commonly known as *ICD-10*), which defines dependence syndrome as “a cluster of physiological, behavioral,

32 In the midst of the debate, there are now proposals to classify drug dependence as a developmental disorder—that is, a condition of the same nature as autism and attention deficit disorder. Szalavitz offers one such proposal, defining drug dependence as “a learned relationship between the timing and pattern of the exposure to substances or other potentially addictive experiences and a person’s predispositions, cultural and physical environment, and social and emotional needs” (Szalavitz 2016, 4).

and cognitive phenomena in which the use of a substance or a class of substances takes on a much higher priority for a given individual than other behaviours” (World Health Organization n.d.).

Dependence on opioids has costly consequences for the individual in question and his or her support network. A joint paper by the World Health Organization, the United Nations Office on Drugs and Crime, and UNAIDS highlights that the social, emotional, and health costs include job loss, homelessness, family disruption, social instability, higher risk of premature death, and, when the drugs are injected, increased risk of transmissible infections such as HIV and hepatitis B and C. The mortality rate for people who use heroin is six to twenty times greater than that of the general population of the same age and sex (World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS 2004, 4–5).

ICD-10 outlines the following core elements of opioid dependence:

- a strong desire or compulsion to take psychoactive substances
- difficulty controlling substance-taking behavior
- withdrawal syndrome when substance use is stopped or reduced
- evidence of tolerance, as shown by the need to increase doses in order to obtain the effects originally produced by lower doses
- progressive neglect of other pleasures or interests
- persistent opioid use despite clear evidence of its harm (*ibid.*, 7)

Regardless of whether it is classified as a medical or a psychological condition, psychoactive substance use disorder is a complex condition that has implications at the neurological, biological, chemical, psychological, medical, emotional, social, political, economic, cultural, and spiritual levels. The desire to use, as well as the associated consequences of such use, are imbued in a complex web of interactions concerning a single individual. Therefore, seeing such dependence as a “disease” inhibits us from considering the other facets involved. Viewing it merely as a disease would also imply that the corresponding solutions are entirely medical, which is not the case. Although the life trajectories of people with drug use disorders reveal many characteristics of disease that do require medical solutions, disease is not the only issue at play (Maté 2010, 138).

Additionally, it is worth noting that age is an important factor to consider when looking at exposure to a substance, as the process of brain maturation means that vulnerability to drug use is heightened during adolescence. Studies show that dependence is very uncommon among

people who initiated their drug use after reaching age twenty-five (Heyman 2013), and in some cases, individuals can recover without treatment (Dawson et al. 2005). Further, 90% of substance use disorders begin in adolescence, and most end by age thirty (Szalavitz 2016, 4). However, a small portion of the population—estimated at 10–20% of those who try drugs—develop a use disorder that cannot be overcome without treatment; it is this group that we focus on in this book.

People in this group tend to share some common traits, particularly childhood trauma and a preexisting mental illness. According to studies from the United States, two-thirds of those who develop drug use disorders have had at least one traumatic experience during childhood, such as emotional, physical, or sexual abuse; rape; abandonment; poverty; or the loss of loved ones (ibid., 65). Nonetheless, experiencing such a personal tragedy does not make drug dependence inevitable, for each individual processes events differently: some react by growing resilient to adversity, while others react through self-destructive behavior, developed during childhood, that eventually leads to problematic drug use in adulthood.

In the United States, one-third of individuals who inject heroin have suffered sexual violence, and half of those with heroin use disorder have experienced emotional abuse and physical neglect, an experience that some researchers have described as “shattered childhoods” (ibid., 65). Heroin’s chemical effects on the brain could explain its use as a self-medication to alleviate the pain of trauma or mental illness: the analgesia produced by opioids act on the brain systems that regulate emotions, allowing for greater tolerance of emotional pain and, to a certain extent, emotional numbness (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33). For people who have suffered childhood trauma or who have untreated or undiagnosed mental illness, this numbness makes heroin an attractive substance due to its ability to make life bearable.

Heroin has the effect of silencing emotions. Many people who have developed an addiction to this drug have an autism spectrum disorder, which makes them especially susceptible to emotions; therefore, the possibility of calming these emotions is practically a blessing. As Szalavitz explains with regard to her own experience with heroin, “every atom in my body felt calm, safe, fed, content, and, most of all, loved” (Szalavitz 2016, 13, 119).

These common characteristics suggest that for many individuals, “drugging” oneself is a form of self-medication that helps alleviate the

person's problems and pain. According to Edward Khantzian's self-medication hypothesis, the drugs that people use are not chosen at random; rather, they are the result of interactions between the substance's psychopharmacologic effects and the prevailing type of pain that haunts a person, and in general, this situation is seen among individuals with preexisting psychiatric disorders (Khantzian 1985).

Studies show that at least half of all people with drug dependence have some other mental health condition or developmental disorder, such as depression, anxiety disorder, bipolar disorder, attention deficit disorder, or schizophrenia. Certain studies even reveal a 98% rate of co-occurring disorders among people with drug dependence. These propensities also interact with the individual's developmental history, including his or her family, educational, economic, and emotional environments (Szalavitz 2016, 39). Cultural factors and the way that individuals learn to perceive, analyze, and process their personal experiences, especially childhood experiences, are crucial for understanding drug dependence. Some longitudinal studies on the risk of developing drug dependence have identified three personality traits that increase a person's vulnerability:

- Impulsiveness, audacity, and a desire for new experiences, which makes it difficult to control one's behavior. These traits are more common among men.
- Sadness, inhibition, and anxiety, which can lead some individuals to self-medicate with drugs in order to deal with negative emotions. These characteristics are more common among women.
- Both of the previous two traits, with behavior that alternates drastically between impulsiveness and being overwhelmed by fear.

Heroin is commonly perceived as a "hard drug" that causes addiction upon its first use. However, the evidence suggests otherwise. Opioids in general—unlike other drugs often associated with addiction, such as cocaine and crack cocaine—are administered in medical environments to patients for various reasons, whether surgery, chronic or severe pain, or other reasons. According to the urban myth that addiction is caused by the substances themselves, any individual who consumes morphine, oxycodone, or hydromorphone following a surgery would be permanently hooked on the drug. The evidence clearly demonstrates that this is not the case, for the fraction of individuals who develop a dependence on opioids after using them for medical purposes is very low, and such cases are generally attributed to conditions that made the person susceptible prior

to the consumption of that substance. Moreover, despite the “good feelings” generated by heroin, according to the US National Institute on Drug Abuse, only 23% of people who try heroin develop a use disorder (American Society of Addiction Medicine 2016).

It is important to highlight that exposure, including prolonged exposure to a substance that can potentially cause dependence, does not entirely account for the development of a drug use disorder. The most emblematic case in this regard is that of American soldiers who fought in the Vietnam War and developed heroin dependence during the horrors of the conflict: upon returning home, the vast majority (95%) of them overcame their dependence. To better understand this apparent paradox, in 1981 psychologist Bruce Alexander carried out experiments with rats aimed at tracking their behavior vis-à-vis such substances. Earlier experiments from the 1960s, whose results had cemented the war on drugs, consisted of analyzing the behavior of caged rats that had only morphine and water available to them. These earlier studies found that the rats began to consume morphine compulsively. Alexander argued that this compulsive behavior was actually due to the animals’ coping mechanism for stress—the stress of being isolated in a cage, with nothing else.

Alexander and his colleagues built a “rat park,” a cage that better mimicked the conditions of a “normal” life of a rat. They then compared the behavior of the “park” rats with the behavior of rats that were caged with just water and morphine. They observed that the rats in the unadorned cage consumed twenty times more morphine than those in the park. The case of the Vietnam veterans points to a similar conclusion: under conditions of extreme stress, one’s susceptibility to developing a drug use disorder increases, but when these conditions improve, the propensity abates (Maté 2010, 142–6).

Maté concludes that three things must simultaneously exist in order for a substance use disorder to emerge: a susceptible organism, a potentially addictive drug, and stress (*ibid.*, 147). With regard to the last factor, a poor person’s risk of developing a drug use disorder is higher, as poverty and low economic and social status tend to increase stress. If the individual has strong support networks, this risk is mitigated; but if the person feels lonely and isolated, it is higher (Szalavitz 2016, 91). Indeed, this was what we observed in the five cities studied in this book, where PWUD were young men, largely from low-income backgrounds, with little educational attainment and few prospects of personal development or steady

income. It is also true that the development of problematic drug use can unleash a process of downward mobility, placing people with high levels of education into homelessness (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 64).

For those who do ultimately develop a dependence on heroin—the population we are focusing on here—it is thus important to ensure access to comprehensive care that goes beyond health care and includes other social services that connect them to training, employment, and housing programs. The health care that is provided, on account of dealing with a multifaceted and complex condition, should respect the basic principles of autonomy, dignity, and informed consent. These aspects are included in the recommendations of the United Nations High Commissioner for Human Rights (2015) in its report on the right to health of PWUD.

Opioid maintenance therapy—the barriers to which we explore in this book—is defined by the United Nations as “the administration under medical supervision of a prescribed psychoactive substance, pharmacologically related to the one producing dependence, to people with substance dependence, for achieving defined treatment aims” (World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS 2004, 12). The most commonly used opioids for such therapy are methadone and buprenorphine, but in Colombia only methadone is available.

Treatment for psychoactive substance use disorder has the potential to address health issues as well as broader social issues if it adheres to the objectives of reducing dependence on illicit drugs, reducing the morbidity and mortality associated with the use of illicit opioids (such as infectious diseases), improving mental and physical health, and fostering social and economic integration. The objective of treatment is not to eliminate the use of opioids—and, in fact, pursuing this aim may jeopardize the achievement of goals regarding the improvement of health (*ibid.*, 8).

Opioid medicines are essential for the treatment and recovery of an individual who wishes to reduce his or her heroin use. Withdrawal symptoms can be devastating and unbearable. Opioid withdrawal syndrome, which lasts between ten and fifteen days, includes nausea, diarrhea, extreme sweating, body aches, physical weakness, severe anxiety, agitation, and depression, among other symptoms (Ministerio de

Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 34).³³

According to United Nations agencies, opioid maintenance therapy should meet the following criteria: “agents used for substitution therapy have been thoroughly evaluated; treatment is administered by accredited professionals in the framework of recognized medical practice; and there is appropriate clinical monitoring” (World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS 2004, 2). For treatment using methadone, the average dose is 60 mg (Szalavitz 2016, 7), although it can vary among patients. The dose administered should eliminate cravings for heroin and reduce withdrawal symptoms. Methadone remains in the body longer than other opioids, for it has a half-life of twenty-four to thirty-six hours, as well as cumulative effects, which accounts for its effectiveness in calming cravings and lessening the uncomfortable symptoms of withdrawal (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33). Opioid maintenance treatment has been shown to reduce mortality by up to 75% (Szalavitz 2016, 130). One systematic review, published in the *Cochrane Database of Systematic Reviews*,³⁴ found that methadone is more effective in reducing heroin use than treatments that do not utilize opioid maintenance, and it also has other positive effects (Mattick et al. 2009). There are few side effects of such treatment, and approximately one-third of those who commence it respond well (World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS 2004, 14).

In conclusion, it is important to highlight some common elements to the two realities that require opioids for medical purposes. One common element that is present among the health workers and professionals who treat these individuals is respect. The practice of palliative care respects patients and their decisions, offering clear and concise information about the progression of their illness and the available

33 Withdrawal symptoms are not limited to drugs that can cause dependence, for antidepressants have also been demonstrated to lead to withdrawal symptoms when stopped—however, this in itself does not mean that the person is addicted to antidepressants. Addiction has an additional layer consisting of cravings and the potential for relapse (Maté 2010, 139).

34 “Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are internationally recognised as the highest standard in evidence-based health care.” See <https://es.cochrane.org/cochrane-reviews>.

options. Meanwhile, as emphasized by the community workers we interviewed for this book, care and treatment for people who use heroin apply the principle of harm reduction, which is based on respect for PWUD, their life decisions, and their autonomy to make decisions about their bodies.

A second element that is shared between the two fields of care is the commitment to seeking solutions in challenging contexts. Speaking from a place of pain—recognizing it, facing it, and imagining a better reality—is a common trait among people who suffer and people dedicated to treating suffering. Palliative medicine and drug dependence treatment bring together individuals who are dedicated to serving populations that society would rather ignore, in order to not see the deep wounds that life can inflict. The bravery and courage that we witnessed during the course of our research convey the ever-present possibility of redemption and relief. The health and drug control systems have the opportunity to take the best of these two worlds and make the highest attainable standard of health a reality—and that possibility exists to the extent that there is life.

The Right to Health in Colombia and Its Relationship with the Regulation of Opioid Medicines

Health care is a constitutional and legal right in Colombia. According to article 49 of the 1991 Constitution, health is a public service for which the state is responsible, and services that promote, protect, and rehabilitate health should be guaranteed for all persons.

Furthermore, the Statutory Health Law (Law 1751 of 2015) defines the right to health as autonomous, fundamental, and irrevocable at both the individual and collective level. This recognition means that the state must guarantee “timely and effective access to quality health services that aim to preserve, improve, and promote health” and that “the state shall adopt policies to ensure equal treatment and opportunities for everyone in accessing activities concerning promotion, prevention, diagnosis, treatment, rehabilitation, and palliation” (art. 2). In addition, article 15 modifies the way in which the scope of the Health Benefits Plan is interpreted, no longer limiting it to a list of covered services and medicines but rather stipulating that the plan must include all services and technologies that

guarantee a comprehensive conception of health, namely through promotion, prevention, palliation, care of illness, and rehabilitation.

Meanwhile, the Colombian Constitutional Court has reaffirmed health as a fundamental constitutional right, which means that the state and private health care providers are obligated to deploy “tasks, activities, or actions directed at guaranteeing the due protection of this right.”³⁵ In addition, “the basic guarantee of the fundamental right to health means that all people must have *effective access to the services they require*.”³⁶

In light of this legal framework on the right to health, IPSs and their staff have the authority to order any service or medicine, including opioids, that they deem necessary for the comprehensive health of their patients. In turn, EAPBs are obligated to ensure that any medicine that is prescribed is made available to their users.

In other words, the legal frameworks regulating both the health system and the drug control system in Colombia have incorporated the necessary standards to guarantee the availability of controlled substances for medical purposes. Nevertheless, as we will see in chapters two and three, these guarantees are not being met in practice due to a series of structural barriers in the health system and the drug control system, as well as social barriers that stigmatize opioids and the people who use them.

Many opioid medicines, including the ones in most demand, are included in Colombia’s Health Benefits Plan.³⁷ Doctors working in the field of palliative care can thus draw on a range of opioids when writing prescriptions, resting assured that the EAPBs are obligated to guarantee their availability and access. In fact, even those medicines that are excluded from the Health Benefits Plan and which require an additional authorization process must be delivered urgently to patients in light of the immediate need for pain relief. With regard to heroin dependence treatment, methadone is included in the Health Benefits Plan and must be available for individuals seeking methadone maintenance therapy. Paradoxically, naloxone—which is essential for reversing an overdose—despite not being a controlled substance, is available only in inpatient settings.³⁸

35 Corte Constitucional, Sentencia T-999 de 2008, October 14, 2008.

36 Corte Constitucional, Sentencia T-104 de 2010, February 16, 2010 (emphasis added).

37 Previously known as the Obligatory Health Plan.

38 The Ministry of Health has developed *Guidelines on the Community Management of Opioid Overdose*, which recommends making naloxone available.

Given opioids' status as controlled substances, the National Narcotics Fund oversees their importation, manufacturing, and distribution, among other things.³⁹ The entity's functions are regulated by Resolution 1478 of 2006, which outlines the control standards for such substances; its article 6 contains a list of the medicines that fall under the state's monopoly—including hydromorphone, morphine, meperidine, methadone, and opium, among others, in all of their forms—and places them on the country's yellow list of narcotic drugs.⁴⁰ Colombia's regulation of these substances is reasonable, for it demarcates certain standards of control and professional training to ensure that they are not diverted to illicit markets.

This resolution also assigns responsibilities to the Regional Narcotics Funds, which are responsible for ensuring the availability of opioids in each department of the country. These entities operate within the structure of department-level secretariats, institutes, or directorates of health, which means that they rely on departmental resources to carry out their functions, including the purchase of opioids from the National Narcotics Fund. They are also responsible for manufacturing the special paper pads used to prescribe opioids (art. 84). As we will see in chapters two and six, these entities are the ones that must handle many of the subnational-level challenges to ensuring the availability of opioids, and they are also the ones that must liaise with the EAPBs and IPSs concerning the sale of opioid medicines at the local level. The norms that regulate the dispensing of controlled substances impose high standards and cumbersome bureaucratic processes that are often used by the EAPBs and IPSs as an excuse for not making these medicines available to their clients.

In terms of general standards, any public or private entity seeking to distribute or dispense opioid medicines must register with the National Narcotics Fund or, if they operate in just one department, the relevant Regional Narcotics Fund. For pharmacies, drug stores, EAPBs, and IPSs, this registration must be accompanied by a photocopy of the professional license of a pharmaceutical chemist, as well as a copy of that person's employment contract. For second- and third-level IPSs,⁴¹ this individual

lable in community settings. See Ministerio de Salud y Protección Social (2017a).

39 The National Narcotics Fund was established via Law 36 of 1939 and is a branch of the Ministry of Health.

40 See annex.

41 Health facilities in Colombia are classified according to four levels of com-

must be a pharmaceutical chemist, while for first-level IPSs, the individual can also be a pharmacy technician. The person who carries out these functions must work a minimum of eight hours a day. This registration is valid for five years. These human resource requirements act as a disincentive to the dispensing of opioid medicines, since they are costly and difficult to fulfill in light of the general lack of qualified professionals in smaller-sized cities, such as Santander de Quilichao.

Facilities seeking to distribute controlled medicines must meet certain minimum requirements with regard to physical infrastructure (art. 36) and human resources (ch. VII). The regulation provides a way out of this difficulty by indicating that in locations where there are no such qualified persons, the departmental health authority must issue a certificate stating as much, which then allows the service to be provided by licensed drug store managers or pharmacists (art. 40).

Finally, chapter XX of the regulation lays out the infractions and sanctions for misconduct concerning controlled medicines. Misconduct is characterized as minor, serious, or very serious, with administrative sanctions applied in accordance with the severity. It is defined as any action that violates the regulation, such as dispensing a medication without a prescription, without being written on official prescription paper, or without the required personnel. Fines range from two monthly minimum wages (about US\$535) to five hundred monthly minimum wages (about US\$134,000).

As we will demonstrate in the following chapters, many health care providers are reluctant to dispense opioid medicines, as doing so adds operational costs and bureaucratic hurdles vis-à-vis local health authorities. While the regulation is reasonable on paper, in practice, especially for a health system whose operation is governed by costs, it acts as a disincentive for these facilities.

Although the rules governing the sale and distribution of opioid medicines has the potential to limit their availability, since 2012 the number of medicines available from the National Narcotics Fund has increased, as shown in the following table. Between 2012 and 2017, the total number

plexity: first-level facilities have general practitioners and other health staff who offer nonspecialized care; second-level facilities have general practitioners, with the option of providing referrals to and advice from specialized personnel; and third- and fourth-level facilities have both specialized and general practitioners.

of opioids available at the national level increased by 83.21%. With regard to the particular case of morphine and methadone in their various forms, availability increased by 36.9% and 37.7%, respectively.

Table 1
Annual availability of opioid medicines
(state monopoly), 2012–2017

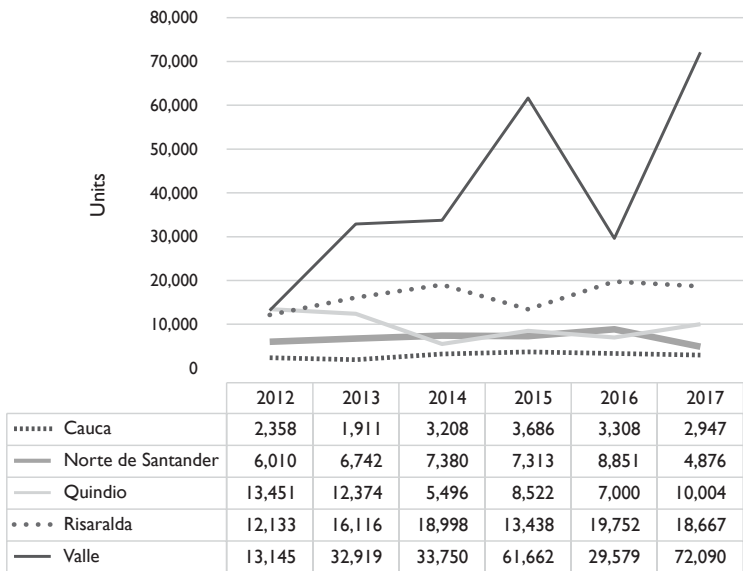
Number of commercial units						
Medicine	2012	2013	2014	2015	2016	2017
Hydromorphone HCl tablets, 2.5 mg	39,210	56,074	53,673	71,225	100,429	99,975
Hydromorphone HCl tablets, 5 mg*	2,690	3,623	5,484	3,942	0	0
Hydromorphone HCl injection, 2 mg/mL	33,904	55,082	67,359	95,660	135,847	173,078
Meperidine HCl injection, 100 mg/2 mL	35,750	42,477	44,785	35,329	35,727	40,128
Morphine HCl oral solution, 3%	61,183	76,188	87,139	83,207	91,690	86,812
Morphine HCl injection, 10 mg/mL	109,929	141,374	167,949	150,596	172,297	147,268
Morphine HCl injection, 3%	12,887	20,733	20,002	15,172	17,034	17,950
Methadone HCl tablets, 10 mg	37,095	43,783	43,894	42,644	43,033	49,821
Methadone HCl tablets, 40 mg	15,027	20,991	18,994	20,906	23,768	21,962
Total commercial units	347,675	460,325	509,279	518,681	619,825	636,994

* Sale suspended in mid-2015

SOURCE: Data provided by the National Narcotics Fund in response to authors' *derecho de petición*, August 8, 2018

However, this increase in availability did not occur equally across the departments where our five cities of study are located. As the next graphic demonstrates, in the departments of Cauca and Risaralda, the number of opioid medicines increased by only 24.9% and 53.8%, respectively, during this period. Further, availability in Norte de Santander and Quindío actually decreased by 28.8% and 25.6%, respectively. The only department that witnessed a considerable increase in the availability of opioids is Valle del Cauca, with an increase of 448.4%.

Figure 3
Opioid medicines purchased from the
National Narcotics Fund, by department



SOURCE: Prepared by the authors with data from the National Narcotics Fund in response to authors' *derecho de petición*, August 8, 2018

These figures show that despite the state's efforts to increase the availability of opioid medicines, there are still barriers at the local level that limit guarantees of the right to health and pain relief for people at the end of life and for people who use heroin and are in need of methadone maintenance therapy. The following two chapters will conduct an in-depth exploration of these barriers for each of these populations.

CHAPTER 2

LIVES ON THE MARGINS: HEROIN USE AND THE SEARCH FOR TREATMENT IN COLOMBIA

HOW WOULD YOU DESCRIBE WITHDRAWAL?

It's the worst, worst, worst thing you can feel—despaired, sick, hungry, I mean, what don't you go through? With methadone, you can gradually lower the dose, quit [heroin], since you take a little pill that lasts all day until the next day. But with this one, it's not like that—you inject yourself in the morning and by the afternoon, you're sick again.

Harold, Pereira, February 2018

Heroin is a semi-synthetic opioid derived from morphine and is two to five times stronger.⁴² Morphine, in turn, is a derivative of the latex of opium poppy (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 32). Opium poppy derivatives have accompanied humanity for thousands of years due to their pleasurable effects, their analgesic and soothing properties, and their promise of relief (ibid., 17–19). Countries began to impose restrictions on opium poppy's production and use toward the end of the nineteenth century,⁴³ and in 1961, the United Nations drug control system established the plant's definitive control by classifying it as a Schedule I drug. Schedule I drugs are the most

42 Heroin was first synthesized in 1874 and was marketed twenty years later by pharmaceutical company Bayer, notably in cough syrup (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 32).

43 “The 1909 Shanghai Conference and the 1912 International Opium Convention at The Hague gave rise to the international drug control system for illicit substances, with thirteen signatory countries at the time, including China, the United States, and the United Kingdom” (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 19).

stringently controlled ones, with criminal sanctions for their cultivation, production, trafficking, and possession (Transnational Institute 2015). In Colombia, sanctions for such conduct are outlined in the Penal Code.⁴⁴

Heroin use in Colombia is a relatively recent phenomenon,⁴⁵ with two possible explanations for its emergence: the presence of opium poppy cultivations and introduction by foreigners (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 22). What is certain, as we will explain in this chapter, is that the country's increased heroin consumption is linked to the confluence of multiple factors that extend beyond simple exposure to the drug.

Besides the stigma of being illicit drug users, people who use heroin carry the additional shame associated with being injecting drug users, which causes even greater societal rejection. While heroin can be smoked, the most prevalent consumption method in Colombia is injection, which poses specific public health challenges that have raised the alarms of local and national authorities. In 2015, the national government published an exhaustive compilation of evidence revealing the magnitude of the phenomenon, the cities where heroin is used, and the consequences of such drug use across the country.

This chapter explores the quest for heroin dependence treatment in five Colombian cities: Cali, Santander de Quilichao, Armenia, Pereira, and Cúcuta.⁴⁶ To understand this quest, we first need to understand the dynamics of heroin use and its impact on the physical and mental health of those who use it. Individuals who seek treatment face a range of barriers that stand in the way of the effective enjoyment of their right to health: structural barriers stemming from the health system, barriers stemming from the opioid control system, and barriers linked to the stigma that

44 Technically defined, a narcotic substance is a drug that produces narcosis (stupor), as is the case of opioids. However, Colombian criminal law uses “narcotics” to refer to any illicit substance, including those that are actually stimulants, and not narcotics, such as cocaine (Scholten 2015, 45). Strictly speaking, and in line with the definition of the World Health Organization, a drug is “any or all substance that, upon introduction into the body, is capable of modifying one or more of its functions” (Calzada 2013, 1).

45 Increased consumption of heroin in Colombia coincides with the rise in demand for opioid treatment in other countries in Latin America, as identified by the Inter-American Drug Abuse Control Commission (2015).

46 In Colombia, heroin use has been identified in Bogotá, Medellín, Armenia, Pereira, Dosquebradas, Cali, Cúcuta, and Santander de Quilichao.

these individuals carry as a result of being “drug addicts” and people who “shoot up.” This population is generally seen as having no way out of their situation, and it is common to hear them described as “lost in drugs” and weak willed.

One story that was recounted to us came from a person who, today, has not used heroin for several years:

The [doctor] came into the room, my mom sat down, and I sat there in front, and the psychiatrist comes in and says, “Look, ma’am, there’s nothing we can do. Once they start using drugs, there’s nothing that can be done. Methadone is just for them to resell [on the street], it only encourages their habit.” That’s what the psychiatrist said.

Together, these barriers contribute to experiences of abuse and loneliness for people who use heroin.

In the face of increased heroin consumption in these cities, government and civil society actors have designed and implemented specific interventions to attend to the needs of this population. However, on the whole, the response to the needs of people in search of treatment continues to be disjointed and insufficient to meet demand, as we will see in this chapter.

This chapter is based on official data sources, national studies, specialized literature, and information gathered during our fieldwork in the five cities. It is divided into four sections: The first explores the magnitude of the problem in each city and the health needs of the population that uses heroin. The second section discusses the legal and policy framework as it concerns the use of psychoactive substances. Finally, the third and fourth sections analyze the pathways for accessing methadone maintenance treatment in these cities and the barriers present in these pathways, as evidenced by information gathered during our fieldwork.

The “Big H”⁴⁷ in Armenia, Pereira, Cali, Santander de Quilichao, and Cúcuta

In 2014, heroin was sold in small bags for an average price of 7,400 Colombian pesos (about US\$2) (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2016, 5). To inject heroin, one first

47 “Big H” is a common name for heroin.

dissolves the powder in water—usually by holding a spoon sideways— heats it, and then places the mixture in a syringe for injection into one’s veins. The effect is almost immediate—it takes just about sixty seconds—and a high of euphoria and pleasure is felt for about fifteen minutes.⁴⁸ Colombian heroin is known for its high potency and low price (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33–34). It is classified as one of the “most harmful” drugs—second only after alcohol—due to the harms it poses to users and those around them (Nutt, King, and Phillips 2010, 1561). According to the Colombian government’s 2015 report on heroin, the epidemiological indicators on heroin use reveal a public health emergency (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 7). Our findings from this research project suggest that this emergency has yet to be resolved and that the country’s response has been insufficient for addressing its magnitude.

In 2015, an estimated fifteen million people across the globe between the ages of fifteen and seventy-four were using injection drugs. Of these, an estimated 1,823,000 were in Latin America, of whom 81% were men and 13% were women (Degenhardt et al. 2017, e1198–9).⁴⁹ According to the most recent *World Drug Report* by the United Nations Office on Drugs and Crime, in 2015 approximately thirty-four million people worldwide had used opioids (including medically prescribed opioids) in the preceding year. Also in 2015, there were 450,000 drug-related deaths, of which 76% were attributable to opioid use (United Nations Office on Drugs and Crime 2018).

Statistics on heroin use in Colombia are few and far between, although there has been a recent effort to estimate the size of the heroin-using population in the seven cities where consumption has been identified. The government’s 2008 national survey on psychoactive substance use found that 4,417 people across the country had used heroin in the past year and 3,082 had used it in the past month (Ministerio de la Protección Social, Ministerio del Interior y de Justicia, and Dirección Nacional de Estupefacientes 2008, 102). Five years later, the same survey found that

48 Opioids can also have uncomfortable side effects, such as nausea, vomiting, dizziness, constipation, and itchiness (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33).

49 The study’s respondents included people who inject either an opioid (including heroin) or a stimulant (amphetamine or cocaine).

7,011 people had used heroin in the past year and 3,592 had used it in the past month (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia and Ministerio de Salud y Protección Social 2014, 100). According to data from the government’s 2015 report, the number of people who injected drugs in 2014 was estimated at 3,501 in Cali, 2,442 in Pereira, 2,006 in Cúcuta, and 1,850 in Armenia, for a total of 9,779 people in those four cities (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 58). In Santander de Quilichao, there are no estimates currently available.

It is worth noting that despite these figures, we cannot know for certain what the size of the heroin-using population is, since just as there are continually new people who begin using the drug, there are also others who die as a result of their heroin use or associated health problems. Although national surveys on drug consumption, which are usually carried out every five years, include heroin use in their questions, they suffer from limitations that are inherent to household surveys—namely, we do not know if they drug-using population is underrepresented. As the National Planning Department acknowledges in its study on the drug trade, its surveys on drug use are unable to reach three key populations: (i) individuals deprived of their liberty; (ii) individuals undergoing inpatient treatment; and (iii) individuals in street situations (Departamento Nacional de Planeación 2017, 29).⁵⁰ For this reason, scholars and government agencies have carried out heroin-specific studies with the aim of reaching these populations, and they reveal significant consumption levels among these populations.

Another useful indicator for understanding the size of the population that uses heroin can be found in reporting by the Drug Observatory of Colombia, which identifies the number of people admitted to heroin treatment programs. For 2012–2017, the observatory reports 1,681 admissions into such programs. Of these, 80% were in the departments of Cauca (94 cases), Valle del Cauca (272 cases), Quindío (353 cases), Risaralda (341 cases), and Norte de Santander (299 cases), the departments where our five cities of study are located (Ministerio de Justicia y del

50 In the 2008 national survey, only thirty-eight people reported having used heroin at some point in their lives, and only six reported using it in the last year, which is far from the reality of heroin use in the country (Ministerio de la Protección Social, Ministerio del Interior y de Justicia, and Dirección Nacional de Estupefacientes 2008, 102).

Derecho – Observatorio de Drogas de Colombia 2019). However, these figures also fail to provide a true picture of reality for two reasons: (i) we do not know whether each admission corresponds to a different person, as there are likely individuals who enter more than once into treatment; and (ii) the observatory's numbers include only those admissions to accredited treatment centers, and there are without a doubt many people who seek treatment from unauthorized centers, foundations, and other nonformal institutions.

In terms of the introduction of heroin use in Colombia, experts point to several factors that converged in order to give rise to this emergency. Drug use—particularly nonritualized use—has generally been associated with industrialized and high-income countries, but in the 1990s developing countries began to show their own increases in drug-use patterns. In particular, the growing consumption of heroin has been identified in areas with significant local production, such as Southeast Asian countries where opium poppies are cultivated (Mateu-Gelabert et al. 2016, 230).

In Latin America, heroin use is attributed in part to the surpluses left by illegal drug trafficking, whereby leftover product is sold relatively cheaply on the local market, thereby generating new demand that, on top of the precarious living conditions among large sectors of the general population, becomes a vulnerability factor for drug dependence. The retail price of heroin is also affected by the dynamics of the global market: around 2010, partly as a result of Afghanistan's strengthened and expanding heroin production, there was a dramatic drop in the price of heroin in Colombia, which decreased from 70,000 pesos (about US\$22.50) per gram in 2008 to 4,000 pesos (about US\$1.20) per gram in 2010 (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 29).

Generally speaking, the factors responsible for Colombia's increase in heroin consumption are the following: increased opium poppy crops and local heroin production; suppression of illegal drug exports, prompting drug traffickers to redirect toward local markets; location along drug transit routes; low retail price and high purity of the substance; and the conditions of poverty and vulnerability experienced by many urban populations. The convergence of these factors, especially the local population's exposure to the drug, thus became a risk factor for the development of heroin dependence (*ibid.*, 31). Our interviews with key stakeholders in

each of the five cities confirm the importance of these factors in contributing to heroin use in these cities.

The cultivation of opium poppy in Colombia began in the 1980s, when cocaine cartels decided to dedicate themselves to the trade, based on business advice from experts in Southeast Asia. The first opium poppy crops appeared in the department of Tolima in 1983, eventually reaching seventeen departments by the 1990s, making Colombia the world's fourth-largest opium producer, with varieties of poppies from Mexico, Thailand, Pakistan, and Iran (ibid., 22). For a brief period in the 1980s, in the El Pato region of Huila, which was controlled by the Revolutionary Armed Forces of Colombia guerrilla group at the time, there was an opium bonanza (Molano 2016, 91). Except for the departments of Nariño,⁵¹ Huila, and Atlántico, the presence of opium poppy crops and laboratories in Colombia coincides almost completely with the cities where heroin is used (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 30).

The Health Impacts of Heroin

Injecting drug use carries significant health risks for individuals in light of the prohibition of these drugs and the societal stigma toward individuals who use them. To start with, heroin—despite its high level of purity in Colombia—has usually been adulterated with other damaging substances by the time it reaches the market.⁵² Once the powder is obtained, it must then be mixed with water before being injected.

Many of the PWUD we interviewed for this book are living in street situations, which means that they have little access to clean water. As a result, they tend to rely on water from puddles or drainage canals to mix the drug, and this mixture—adulterated heroin and dirty water—is what enters the bloodstream. Farther along this risky journey, and as recounted to us by community workers who run needle-exchange programs, syringes are a scarce commodity in drug-using circles, for a variety of reasons: cost, confiscation by police, and pharmacies' refusal to sell syringes to PWUD. This means that syringes are usually shared among several people, which

51 In Nariño, heroin production is thought to be supplying and aggravating emerging use on the Ecuadorian side of the border. See Clavel (2018).

52 A 2009 study by the Institute of Forensic Medicine found the following adulterants in heroin: caffeine, phenacetin, levamisole, aminopyrine, diltiazem, and terephthalate (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 35).

increases the risk of blood-borne infections such as HIV and hepatitis B and C. Finally, the practice of repeatedly injecting oneself carries the risk of developing abscesses or collapsed veins.

Police and social persecution don't help, either, as people who use heroin are routinely rounded up by police officers, which impels them to try to inject the drugs quickly in dark and secluded areas, thereby increasing the already high risks. In the words of a community worker, "The fact that the police corner users from all sides makes them hide even more and use even more drugs because of society's rejection." Injection heroin use is the main method of consumption used in the cities analyzed in this book, except for Santander de Quilichao, where the main method is smoking.

The illegality of these substances means that they are often adulterated or "cut" (diluted) in order to increase dealers' profits. Between 2014 and 2015, the Colombian government conducted an in-depth study on the heroin market and heroin purity in the seven cities where it had identified consumption: Armenia, Bogotá, Cali, Cúcuta, Medellín, Pereira, and Santander de Quilichao. It analyzed 136 drug samples destined for retail sale, finding that 117 of the samples were indeed heroin⁵³ with varying degrees of purity. On average, these samples were 62.7% pure, significantly higher than in other countries where opioids are consumed.⁵⁴ However, purity varied across cities: Armenia (79.2%), Bogotá (85.9%), Cali (47.2%), Cúcuta (43.7%), Medellín (47.2%), Pereira (70.1%), and Santander de Quilichao (31.2%). As these results show, heroin purity is highest in Quindío and Risaralda, while in Santander de Quilichao it is relatively low. In terms of adulterants and substances used to cut the product, the government found that caffeine is the most common substance used (69% of the samples) (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2016, 4–5).

Furthermore, after prolonged heroin use, individuals develop tolerance, which means that they need a larger amount to achieve the same effect. This tolerance is lost once they stop using the substance, such as after

53 The remaining samples were as follows: six were crack cocaine, three were a mixture of non-narcotic substances, one was morphine, and nine were mixtures containing traces of heroin (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2016, 4).

54 According to a report by the European Monitoring Centre for Drugs and Drug Addiction (2017), heroin purity in Europe ranges between 16% and 33%.

going through detox. Thus, the moment when an individual completes a treatment program is an extremely vulnerable one, for if they end up consuming the same dose as previously, they run the risk of suffering an overdose (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 33–34).

Injecting heroin poses public health risks in addition to personal risks. For example, it has been shown that unhygienic injecting drug use can cause HIV prevalence to explode in a very short amount of time, first among those who inject drugs and then among the general population (Pan American Health Organization and UNAIDS 2001, 28). The first cases of HIV among Colombia’s drug-using population were identified in 1999 (Mateu-Gelabert et al. 2016, 231).

The risks for people who inject drugs are very high. According to UNAIDS (2014, 173), HIV prevalence among this population is twenty-eight times higher than among the general population. While these risks are associated with needle sharing and unhygienic injection practices, our research in the five cities shows that these practices stem in part from the criminalization and stigmatization surrounding drug use: police are continually confiscating drug paraphernalia, and pharmacies often refuse to sell syringes to PWUD because they see such sales as “encouraging” drug use. When PWUD are offered the possibility, through needle-exchange programs, of having new needles and syringes for each injection, they prefer this option.

Worldwide, new HIV infections have declined, but this is not the case for populations who inject drugs, who still experience outbreaks of HIV and other transmissible infections. With regard to hepatitis C, according to a report in the *Lancet*, 50% of the global population of people who inject drugs are exposed to the virus (International Expert Group on Drug Policy Metrics 2018, 11).

In light of the above, it is clear that stigmatization and the threat of punishment enhance, not limit, the risks of heroin use, while also having additional consequences that endanger this population’s right to life. There is increasing evidence that the criminalization of drugs negatively affects prevention and treatment efforts aimed at people living with HIV or hepatitis B or C due to their fear of mistreatment (ibid. 2018, 11).

A 2003 study from the United States followed 1,300 injecting drug users over a twelve-year period. Those who had been incarcerated during this time were the least likely to be among the 20% who eventually stopped

using drugs (Galai et al. 2003). Another study from Canada for a similar population of 1,600 individuals found that incarceration decreased the odds of recovery by half (DeBeck et al. 2009). Policies of incarceration and repression are driven by the misguided premise that taking the substance away from the individual—whether through confiscation or the deprivation of liberty—will solve the problem (Szalavitz 2016, 179). This premise neglects the fact that recovery is much more than detoxification and that such policies produce more anxiety and distress for people who find themselves in situations of vulnerability, without offering the necessary tools for recovery.

Risky injection practices include the following: injecting oneself in open spaces, sharing needles and syringes with others, failing to sterilize injection equipment, using pre-filled syringes, and selling drugs. One study from 2016 on the risky patterns of injecting drug use in Medellín and Pereira⁵⁵ found that 76% of respondents had injected themselves in an open setting, 42% shared their needles with others, and 44% had been involved in the sale of drugs. Among those who shared needles, 59% did so because they did not have access to other needles; it is also worth noting that 55% of the study's respondents had had their injection equipment confiscated by the police during the previous six months. In other words, the state's actions, such as seizure of drug paraphernalia, often work against the safeguarding of drug users' health. The study also found that 31% of respondents never cleaned their needles and 19% did so only on occasion.

Some of the risks associated with heroin consumption can be reduced by applying a harm reduction approach in the health policies that concern this population. According to Harm Reduction International:

Harm reduction refers to policies, programmes and practices that aim to minimise negative health, social and legal impacts associated with drug use, drug policies and drug laws. Harm reduction is grounded in justice and human rights—it focuses on positive change and on working with people without judgement, coercion, discrimination, or requiring that they stop using drugs as a precondition of support. (Harm Reduction International 2019)

55 The respondent sample consisted of 242 people from Medellín and 298 people from Pereira. Of these, 93% were men, 77% had low-income backgrounds, more than half engaged in poly drug use, and their average age was twenty-five (Mateu-Gelabert et al. 2016, 231).

For people who use heroin, harm reduction entails a series of interventions that are non-abstinence based and that include health services, social services, and treatment options for those who want them. Harm reduction interventions are low threshold—in other words, accessible—and are “committed to meeting [individuals] ‘where they are’ in their lives” (ibid.). Such interventions also generally include needle-exchange programs in order to reduce the risks associated with injection. However, they are not limited to needle-exchange efforts; rather, they seek to foster safe settings for people who use drugs by offering information on good injection practices and facilitating referrals to other social and health services. They also have operating hours that cater to the target population and are located near consumption sites in order to reduce transportation burdens. These sites, denominated “listening centers,” are based on participatory community processes, and they facilitate services and actions such as shelter, active listening, support, training, education, and referrals to other services (Ministerio de Salud y Protección Social 2015). In the words of a worker at one such center, “We deliver what we promise. We understand that we need to stick it out for them.”

Despite evidence of the efficacy of harm reduction interventions in improving the quality of life of PWUD, and improving public health generally, our field visits revealed that such programs in Colombia are insufficient to meet existing demand and are in dire need of financing from health authorities and social welfare services. Meanwhile, heroin use places these individuals in settings that increase their vulnerability and stigmatization, thereby widening their social, emotional, and economic distance to health services.

The risk of HIV infection is higher among people who inject drugs⁵⁶ than among the general population, which in itself places these individuals in a more vulnerable situation. According to the studies that were compiled for the government’s recent report on heroin, HIV prevalence in 2014 among people who use drugs was reported to be 8.9% in Pereira, 2.7% in Armenia, and 6.7% in Cúcuta. In Cali, the percentage was 3.5% in 2012, and there were no data for Santander de Quilichao (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 84).

56 The population of people who inject drugs does not consist exclusively of people who use heroin.

Between 2011 and 2014, researchers conducted a study in six cities with a presence of injecting drug use.⁵⁷ Their results reveal certain generalities among people who use heroin: 89% are men, the average age is twenty-six, most have a high school education, the average history of heroin injection heroin is four years, and the main source of income is street selling. The report concludes that Cúcuta has the highest HIV prevalence (5%) and that, in general, the other cities have relatively low prevalence (1–3%) considering the risky practices that were identified (Berbesi-Fernández et al. 2016, 73).

Each city has its own history of heroin use, as well as a unique geography of such use within the urban fabric. Armenia, according to Quindío's Secretariat of Health, is a drug corridor, and heroin is relatively cheap there. In addition, according to some of our interviewees, many residents who lived through the city's 1999 earthquake suffered mental trauma that was not addressed in a timely manner and which could have served as a contributing factor to developing drug dependence.

Heroin use in Pereira, according to popular lore, emerged after the head of the cartel that controlled the city's heroin business was sent to prison. When this happened, the other members of the cartel were left with all of the drugs, so they began to give them away for free in various neighborhoods.⁵⁸ Some of our interviewees also explained that today, no one is allowed to inject heroin in the *ollas* (street drug markets) of Pereira due to the fact that the son of a cartel boss died from an overdose, prompting the drug lord to ban its use in the city. As a result, people who use heroin must travel to the neighboring city of Dosquebradas to be able to inject.

In the case of Santander de Quilichao, interviewees told us that local gangs laced marijuana joints with heroin and gave them away in poor neighborhoods in order to get people hooked on the drug.⁵⁹ In Cúcuta, heroin use has existed since 2001, but according to interviewees, increased controls along the Colombia-Venezuela border between 2009 and 2015 meant that the drug traffickers could no longer transport their drugs

57 The study sample consisted of 1,464 people who actively consumed drugs (240 in Medellín, 300 in Pereira, 240 in Cali, 265 in Armenia, 210 in Cúcuta, and 198 in Bogotá). It found a profile similar to that revealed in the 2016 study: 88.9% were men, and the average age was twenty-six (Berbesi-Fernández et al. 2016, 72).

58 Interview, Pereira, February 2018.

59 Interview with an individual who uses heroin, Santander de Quilichao, November 2017.

to Venezuela. Thus, small and medium dealers were left with the surplus heroin and began to give it away to local residents, especially university students and people from the upper-middle class. Later, they began giving it away to residents of low-income neighborhoods, who, once hooked, proved loyal clients.⁶⁰ Meanwhile, in Cali, it is said that heroin surpluses began to be sold on the local market due to the city's status as an international distribution center, although another local legend claims that foreigners who used heroin arrived to the city in the 1990s and popularized "shooting up."

The initial years of heroin consumption in Colombia were a confusing time for families, health practitioners, and authorities. Many young people began arriving to hospital emergency rooms with withdrawal syndrome, but no one knew what it was or what was causing it. In Armenia, health workers initially thought that there had been an outbreak of dengue. Gradually, they began to realize that these cases were due to heroin use.

Today, the geography of heroin use varies from city to city. In Cali, heroin use is concentrated along a single street known as Calle del H, located downtown, just a few blocks from an *olla*. Cúcuta, meanwhile, does not have a specific area: people who use heroin are spread throughout various areas of the city according to population group, such as trans women and sex workers. In Pereira, heroin consumption has increasingly relocated to Dosquebradas, mostly in an *olla* located in a poor neighborhood. Santander de Quilichao does not have specific consumption points, as police persecution causes people who use drugs to continually be on the move. Finally, in Armenia, consumption points are located downtown, not far from the mayor's and governor's offices.

These geographies of consumption are relevant because in order for a harm reduction or methadone maintenance program to function, it must consider the itineraries, movements, and practices of people who use heroin. As we will explain in the following section, physical distance is often a key barrier to accessing health services.

The five cities, as we will see later, share the challenge of providing comprehensive care to people who use heroin, which requires recognizing PWUD as human rights subjects just like anyone else.

60 Interview with staff member of Consentidos Listening Center, Cúcuta, October 2017.

Legal and Policy Response toward People Who Use Drugs

Over the last twenty years, the Colombian government has developed laws and policies to address problematic drug use in the country. Its response has evolved from a repressive focus to one centered on human rights and public health. In this section, we offer an overview of these legal and policy initiatives and discuss how the Constitutional Court has played a key role in ensuring their application in practice.

Legal Situation of People Who Use Drugs

First, it is important to take a brief look at the legal situation of PWUD, considering that the Colombian government has historically responded to the problematic consumption of drugs through criminalization instead of a public health approach. Since 1936, drug-related offenses in the Penal Code have increased, as have the penalties associated with those crimes. According to a study by Rodrigo Uprimny et al. analyzing the evolution of drug-related criminal law, there is a “tendency to increase the use of criminal law without considering its effects on the enjoyment of human rights and on the phenomena it seeks to address” (Uprimny Yepes, Guzmán-Rodríguez, and Parra Norato 2013, 11).

Prior to 1994, people who used drugs in Colombia could be imprisoned for up to thirty days and charged with a fine of half the monthly minimum wage. A person arrested twice in twelve months could be incarcerated for up to a year and a month, and the fine could be between half and an entire monthly minimum wage. Further, if a legal-medical opinion found the person to be in a “state of drug addiction,” the person could be committed to an “official or private psychiatric or similar establishment for the duration necessary for their recovery,” and the costs of such treatment would need to be covered by the person’s family. It could thus be argued that Colombia’s social conception of PWUD has been influenced by moralistic views about the use of psychotropic drugs. These provisions were declared unconstitutional by Sentence C-221 of 1994, in which the Constitutional Court found them in violation of the rights to free development of personality, to self-determination, and to personal dignity.⁶¹

The court’s ruling held that mandatory medical treatment was unconstitutional on two grounds. First, if one considers such treatment to be a criminal penalty, it would be punishing a person for personal drug

61 Corte Constitucional, Sentencia C-221 de 1994, May 5, 1994.

use, which is not a crime. Second, obligating a person to receive medical treatment violates their liberty and personal autonomy by subjecting them to the will of a judge or physician. As the court noted, “Everyone is free to choose which of their illnesses are treated and whether to recover their ‘health.’”⁶²

The decriminalization of drug use was a first step toward viewing drug dependence from a perspective other than a punitive one. Following this ruling, Colombia began to develop norms, programs, and plans to address drug use, and today the government recognizes the problematic use of psychotropic substances as a public health issue.

Health Policies concerning People Who Use Drugs

Given that our focus is on the barriers to accessing opioids needed for methadone maintenance therapy, our public policy analysis will center on access to treatment for psychoactive substance use disorders. Over the last decade, the government has begun to develop a differentiated response, particularly concerning the needs of people with heroin use disorder, which we will address at the end of this section.

One of the first attempts to address the problematic use of psychotropic substances was in 1998, through the Ministry of Health’s adoption of the National Mental Health Policy (Resolution 2358 of 1998). This resolution includes a set of technical and administrative guidelines for EAPBs and IPSs, among other entities. The resolution’s annex, which is dedicated to “reducing the risk of psychoactive substance use,” analyzes various aspects of the use of these substances and outlines how public health policies should address the problem. First, it establishes that the objective of such policies should be to reduce the use and abuse of psychotropic substances and to “offer, wherever possible, safe and agreeable use that is respectful of individual liberty while decreasing the possible harmful effects on individuals, their families, and society” (sec. 1.5).

In addition to differentiating between substance use and substance abuse, as well as the implications of each, this policy recognizes that “the quest for a drug-free society is unrealistic” and notes that the state should focus its efforts on education and care, as opposed to repression and punishment, for those who use drugs. Following this premise, the policy incorporates a harm reduction strategy that seeks to mitigate the problems associated with the use of these substances, including the transmission of

62 Ibid., p. 22.

diseases such as HIV and hepatitis. This approach implies that “the state has the obligation to inform the population of the individual risks inherent in the consumption of psychoactive substances. Likewise, the duly informed adult population that decides to consume these substances has the obligation to refrain from exposing others to additional harm” (sec. 4).

The annex to Resolution 2358 acknowledges Colombia’s increase in heroin consumption—which grew from 0.06% in 1993 to 1.2% in 1997—and concludes that 10% of individuals who use heroin do so via injection. In light of this situation, the policy establishes the need to strengthen primary health care programs for this population, including methadone maintenance therapy and the development of “guidelines for the comprehensive care of people with psychoactive substance addiction” (sec. 4.4.1).

The following year, through Decree 1943 of 1999, the government established the Presidential Program against Drug Abuse (known as Rumbos), which it tasked with the prevention, treatment, and rehabilitation of psychoactive substance use disorders—a responsibility that, until that point, had belonged to the now-defunct National Directorate for Narcotics. The program sought, among other things, to design comprehensive prevention campaigns with a community focus; promote the development of family solidarity and responsibility; foster the conservation of physical and mental health; conduct research on the magnitude of the problematic consumption of psychotropic substances; strengthen the National Prevention System for Psychoactive Substance Abuse; and coordinate various authorities’ educational policies on prevention.

To implement the Rumbos program, in 2000, the government issued a comprehensive prevention policy document aimed at addressing the use of psychoactive substances. According to the document’s analysis, at that time in Colombia, there were approximately 300 treatment facilities with the capacity to treat 12,000 individuals. Of these facilities, 95% were private and operated with little government oversight, which enabled them to employ non-evidence-based treatments. In spite of these findings, just 16% of the budget for the Rumbos program’s implementation (41,564,000,000 Colombian pesos, or about US\$13.4 million, for four years) was allocated to the Ministry of Health, the entity responsible for strengthening treatment and rehabilitation programs (Departamento Nacional de Planeación 2000).

Two years later, the Ministry of Health issued Resolution 196 of 2002 on the “technical, scientific, and administrative norms for the functioning of comprehensive care, treatment, and rehabilitation centers that provide health services to people with problems associated with the consumption of psychoactive substances.” This resolution was directed toward “comprehensive addiction care units” within public hospitals and toward “centers for comprehensive, care, treatment, and rehabilitation,” which were public and private IPSs that offered prevention, treatment, and rehabilitation services for PWUD (arts. 1, 2). According to the resolution, these centers were to include first-, second-, and third-level health facilities. First-level facilities would offer drug use prevention programs. Second-level ones would offer prevention services and “low-complexity treatment that does not compromise the client’s integrity.” Lastly, third-level facilities would develop “more specialized and complex activities required for the treatment of people with drug addiction” (art. 4).

Until 2006, Colombia lacked regulations on the accreditation process for drug dependence treatment facilities, and service provision at these centers was not monitored. Regulations were issued in 2006 via Resolution 1315 of the Ministry of Health. The resolution’s aim was to regulate the quality of health services that would now be called “drug addiction treatment centers” (art. 1), which the resolution defined as “any public, private, or mixed institution that offers health services for the treatment and rehabilitation, whether residential or outpatient, of people addicted to psychoactive substances, through the application of a particular evidence-based care model or approach” (art. 2).

In 2007, the Ministry of Health issued the *National Policy for the Reduction of the Use of Psychoactive Substances and Their Impact*, whose main objective was to “reduce the incidence and prevalence of the consumption of psychoactive substances in Colombia and to mitigate the negative effects of consumption on individuals, families, communities, and society” (Ministerio de la Protección Social 2007, 18). Among the strategies proposed by the policy were actions aimed at ensuring that PWUD do not develop a problematic use of these substances and preventing these individuals from assuming drug-related risks concerning their physical and mental health.

Concerning treatment, this policy recognized that one of the main barriers to overcoming problematic drug use was the lack of covered treatments and thus recommended that health care plans be urgently expanded

to guarantee access to treatment, particularly for the most serious and priority cases. It also proposed that service provision be accredited, adjusted to meet demand, and offered in accordance with “geographic areas, socio-economic groups, gender, use patterns, and co-morbid conditions” (ibid., 22).

This policy was subsequently operationalized in the *2009–2010 National Plan to Reduce Consumption*, drafted by the National Commission to Reduce Drug Demand. The commission later updated this plan for 2011–2014; however, it was never formally issued, much less implemented (Ministerio de Salud y Protección Social 2017b).

In 2009, Congress approved Legislative Act No. 02, which added a paragraph to article 49 of the Constitution concerning the right to health. According to this paragraph—which prohibits the carrying and consumption of psychoactive substances—the law will establish “administrative measures and treatments of a pedagogical, prophylactic, and therapeutic nature for people who consume these substances.” Although the intention of the first part of this paragraph was to return to punitive drug control measures, its call for actions related to treatment meant that, in spite of this regression, the government maintained its focus on public health as part of the country’s drug policy.

In 2012, through the passage of Law 1566 enacting “rules to ensure the comprehensive care of people who use psychoactive substances,” the government made significant progress concerning the health system’s obligation to provide comprehensive treatment for individuals with psychoactive substance use disorders. Law 1566 acknowledges substance abuse as a public health problem that requires the attention of the state (art. 1). In addition, it guarantees the right of all persons with drug use disorders to receive the necessary care from relevant actors of the health system and requires that such treatment be included in the health benefit plans both for the subsidized regime and for the contributory one (art. 2). In particular, the law refers to the inclusion of “clinical and therapeutic plans and procedures, medication, and activities that ensure comprehensive and integrated care for people with mental disorders or any other pathology derived from the consumption of, abuse of, and addiction to illicit psychoactive substances, which allow for full psychosocial rehabilitation and recovery of health” (art. 2(1)).

Moreover, the law establishes that these services will be provided by IPSs at the various levels of care and through Ministry of Health

programs, such as user-friendly services, mental health units, community care centers, and basic health care teams. The facilities that provide these services must be accredited by the relevant departmental secretariat of health (art. 3) and will be fined if they fail to meet the established requirements (art. 5).

The passage of Law 1566 was a critical step forward in the development of a public health policy concerning the problematic use of psychoactive substances, for it established access to treatment as a human right and thus an obligation of the health system. In theory, this recognition means that any individual affiliated with the health system—which offers universal protection—can receive such treatment regardless of their economic capacity, which was previously a key obstacle for people seeking such treatment. In addition, the EAPBs are required to contract IPSs that have the technical knowledge and infrastructure to offer these services to their members. Unlike earlier standards on mental health and psychoactive substance use, this law establishes concrete obligations concerning the problematic use of drugs that go beyond mere prevention strategies. Finally, the requirement that IPSs be accredited to provide these services means that such treatment must be evidence based and scientifically sound, which protects patients from malpractice, abuse, and scams.

This law is also an important step forward in the protection of the rights of PWUD because it embraces a public health approach to addressing their needs, especially the need to ensure access to evidence-based treatment that is respectful of their rights as users of the health system. Nonetheless, as the following sections will demonstrate, there remain numerous barriers in the administrative, budgetary, and social realms that prevent the successful implementation of Law 1566 and thus the effective enjoyment of the right to health of PWUD in search of treatment.

The need for a strengthened public health and human rights focus in drug policy was supported by the Advisory Commission on Drug Policy, which between 2013 and 2015 published two reports analyzing drug consumption in Colombia, evaluating the impact of the state's responses to date, and proposing an approach rooted in international human rights and the best practices of countries that have reformed their drug policies on the basis of scientific evidence.

The commission argued that the adoption of a public health approach to Colombia's drug policy "requires regulatory actions geared toward consumption and intersectoral policies that offer adequate tools for

the prevention of drug dependence and problematic consumption, as well as care, treatment, and harm reduction” (Comisión Asesora para la Política de Drogas en Colombia 2015, 10). Based on this premise, the commission recommended, among other actions, that the state “ensure the quality of existing treatment and of the facilities that provide it, whether they be public or private. This is especially important in the case of children and adolescents and should be achieved through permanent evaluation processes” (ibid., 29).

The most recent policy in this regard is the *2014–2021 National Plan for the Promotion of Health and for Psychoactive Substance Use Prevention and Care*. This plan takes stock of the impact of policies to date and provides a new set of guidelines to strengthen the public health and human rights focus that earlier policies had begun to carry forward. The plan’s main objective is to “reduce the magnitude of drug use and its adverse effects through a coherent, systematic, and sustained effort on drug use prevention and care for individuals and communities affected by it, accompanied by strengthened information systems and oversight in public health” (Ministerio de Salud y Protección Social 2017b, 31). To this end, the plan proposes five components aligned with the *Ten-Year Public Health Plan*: institutional strengthening, health promotion, prevention, treatment, and harm and risk reduction (ibid.).

With respect to treatment, the aim is to “improve the availability of, access to, and quality of services for individuals who use psychoactive substances” (ibid., 40). To achieve this goal, the plan proposes two strategies: (i) strengthen processes around the provision of treatment, which requires conducting a census of providers and creating evidence-based guidelines for treatment, and (ii) work with EAPBs to improve the delivery of existing services and strengthen monitoring and evaluation mechanisms for the IPSs. In particular, in its provisions on the responsibilities of local entities, the plan states that EAPBs and IPSs should include budget lines that ensure access to treatment under the terms established by Law 1566 (ibid.).

The *National Response Plan for the Rising Use of Heroin and Other Injected Drugs* was created in 2013 and includes four strategic lines: prevention, impact mitigation, strengthening of care and treatment, and capacity building. Importantly, the plan recognizes PWUD as

subjects of both rights and duties, and even when they may or may not have been diagnosed with a drug use disorder, they are responsible for their well-being and that of those around them, they are equipped with the capacity to transform their reality, and they require only the means, spaces, and settings to make this feasible. Furthermore, users of these substances have a series of needs in addition to those deriving from drug use, which calls for a comprehensive perspective that allows for an approach centered on the person and not merely on part of the “problem.” (International Organization for Migration and Mayu of New England 2013, 18)

The prevention component is focused on reducing the risks associated with the consumption of psychoactive substances, including the onset of or lead-up to heroin use, the development of a heroin use disorder, and the transition from smoking to injecting. In this regard, it calls for early detection and intervention, health- and rights-related education, and the adoption of prevention methods, such as condom distribution. Such actions should be directed to individuals who do not consume psychoactive substances but who socialize in settings where these drugs are used, to individuals who consume other psychoactive substances and who socialize in settings where heroin is consumed, and to people who use heroin in non-injection forms (*ibid.*).

The plan’s mitigation component is focused on mitigating harms associated with established heroin use. In this regard, its actions are directed solely toward people who have a heroin use disorder or who inject heroin, and they are based on one-on-one contact as opposed to massive campaigns. Among its action lines are the delivery of hygienic injecting materials; condom distribution; the detection, diagnosis, and treatment of illnesses such as HIV, hepatitis, and tuberculosis; and referral to comorbidity treatment for individuals with mental illnesses. It also proposes the development of health-related education focused on behavior change and overdose prevention, as well as the implementation of psychosocial support measures (*ibid.*).

In terms of care and treatment, the plan seeks to expand and strengthen treatment services at all levels of care provision and to eliminate barriers to access for patients. Its action lines include the delivery of opioid-assisted detoxification and opioid maintenance therapy, complemented by constant and comprehensive psychosocial care aimed at improving

adherence to and the effectiveness of treatment. It also calls for steps to prevent the shortage and diversion of medicines such as methadone. Additionally, the plan proposes the creation of a unified registry for people undergoing treatment that is aligned with SuiCad, the country's Single System of Indicators for Drug Addiction Care Centers (ibid.).

Finally, the capacity building component is focused on improving the capacities of health personnel and community workers. In this regard, it recommends that these individuals be trained on the relevant legal framework, human rights, and technical aspects, such as HIV screening, treatment, and monitoring. It also calls for the development of an early warning system (ibid.).

In 2015, in light of increasing heroin use in the country, the Ministry of Justice sponsored the aforementioned study on the production, use, and public health impact of heroin in Colombia. This report provides a set of public policy recommendations that incorporate strategies for prevention, harm reduction, treatment, and institutional capacity building. In particular, with respect to treatment, the report emphasizes the need for institutions to

offer comprehensive psychosocial and physical and mental health care. Treatment should not be understood as an inevitable path that will ultimately lead to permanent abstinence from all drugs regardless of their particularities. Substitution treatment has shown that it is possible to lead a fully functioning and integrated life even with the presence of a chronic dependence. With constant, good-quality, and comprehensive psychosocial support, it is possible to overcome illicit drug use, connection to crime, and high-risk behavior, among other things, which are ultimately the factors responsible for the negative social and health impact of these practices. (Ministerio de Justicia y del Derecho – Observatorio de Drogas de Colombia 2015, 106)

Within the framework of the *2014–2021 National Plan for the Promotion of Health and for Psychoactive Substance Use Prevention and Care*, the government developed a protocol in 2017 for the treatment of opioid overdose. This protocol offers evidence-based guidelines on the emergency use of naloxone to reverse the effects of an opioid overdose and thus reduce overdose mortality rates. Among the issues addressed in the protocol are instructions for first aid and the emergency treatment of an

overdose, the availability of naloxone, and guidance for the education and training of medical and community workers (Ministerio de Salud y Protección Social 2017a). In 2018, the Ministry of Health issued internal instructions to EAPBs reminding them of their duty to provide health care—including medicines—to people with substance use disorders and emphasizing these individuals’ status as rights holders.⁶³

Following the passage of Law 1566, the Constitutional Court continued to receive cases centering on the denial of treatment for psychoactive substance use disorders, even though this law states that such treatment should be provided within both the subsidized health regime and the contributory one. In the initial lawsuits following the law’s passage, EAPBs generally defended their denial of such treatment by arguing that their technical scientific committees found it unnecessary for the patient in question. In several cases, the court ordered EAPBs to authorize the treatment, noting that it should be “suitable, continuous, and effective [and administered] in a center or facility that has the necessary experience and capacity to provide this type of service.”⁶⁴ In other cases, the court ordered the EAPBs to conduct timely and technical diagnoses in order to determine the patient’s need for treatment.

In more recent rulings, the Constitutional Court has incorporated the provisions of Law 1566 into its analyses and, in addition to granting claimants’ access to treatment, has begun to develop standards with which the EAPBs and IPSs must comply when providing treatment for psychoactive substance use disorders. For example, in Sentence T-043 of 2015, citing a 2012 report of the United Nations Office on Drugs and Crime on best international practices in drug dependence treatment and care, the court noted that such treatment should (i) adopt a human rights-based approach, keeping in mind that drug dependence is a public health problem and not a criminal offense; (ii) obtain the patient’s free and informed consent in all cases, save for “exceptional cases of emergency, unconsciousness, or risk of death [in which] it is acceptable for doctors to act in accordance with the principle of beneficence in order to preserve the patient’s life”; (iii) be available and accessible for patients in terms of “location, operating hours, wait time, and safety”; (iv) prioritize integration

63 See Superintendente Nacional de Salud, *Circular 002 de 2018*, April 12, 2018, <https://docs.supersalud.gov.co/portalweb/juridica/circularesexterna/circular%20externa%20no.%20002%20de%20202018.pdf>.

64 Corte Constitucional, *Sentencia T-792 de 2012*, October 11, 2012, p. 28.

over isolation; and (v) offer multidisciplinary assessment and support.⁶⁵ With regard to this last item, the court explained that

to guarantee that patients/users are treated in a timely manner and in accordance with their needs, [the court] recommends an initial emergency assessment to determine the first steps that must be taken. Treatment should then be drawn up jointly by a multidisciplinary team of physicians, psychologists, and social workers, given the multiple facets and impacts of drug addiction, not only in the physical arena but also mental, family, and social ones. Such programming should be based on available scientific evidence.⁶⁶

As seen in this section, there is a broad set of standards addressing psychoactive substance use disorders and seeking to ensure an adequate health system response. Although these policies have evolved over the last twenty years toward a focus on comprehensive care for the problematic use of drugs and have made progress in adopting differentiated approaches such as those required by people who inject drugs, in practice many legal and administrative hurdles continue to stand in the way of access to such care. As we will see in the following section, many people in need of treatment have had to take legal action in order to secure the protection of their right to health, which has triggered the development of a body of constitutional jurisprudence on the rights of people with drug use disorders. The Constitutional Court's decisions in this regard have established that such individuals are the subjects of special protection and that the state, through its health system, is obligated to provide them with comprehensive care.

Access to Methadone Maintenance Therapy

Pathways to treatment for individuals who use heroin must necessarily be based on a process of trust building, given that many of them have suffered personal trauma; mistreatment and abuse by the police; and negligent treatment at health clinics and centers. Community centers and listening centers—which are generally near locations where drugs are used—are the institutions that fulfill this trust-building function and are

65 Corte Constitucional, Sentencia T-043 de 2015, February 4, 2015, p. 26.

66 *Ibid.*, p. 27.

able to lay the foundation for the path toward treatment for those who wish to pursue it.

The journey is a long one, and in some cases the first steps are extremely basic, such as obtaining a *cédula* (Colombian identity card). In theory, the first step should be an appointment with a general practitioner, who then refers the patient to a psychiatrist in order to determine whether the patient requires hospitalization or outpatient treatment. However, this step is often inhibited by the fact that many individuals seeking treatment do not have a *cédula*, are not affiliated with an EAPB, or do not know which EAPB they belong to. On top of these barriers are the long wait times usually involved in securing an appointment.

According to a study by the nongovernmental organization Observatorio Así Vamos en Salud, the wait time for an appointment with a general practitioner has a rating of 23 for EPSs and 9 for IPSs. Meanwhile, users' perceptions of these wait times have a rating of 45 for general practitioners, 29 for specialists, 52 for dentists, and 52 for preventative health programs. The study categorizes results on a scale of 0 to 100 as follows: good (75–100), satisfactory (60–74), and poor (0–59) (Observatorio Así Vamos en Salud, 2017). In other words, according to the index, the ratings for appointment wait times all fall into the “poor” category. Furthermore, the proportion of health care users who find that it is easy to access health services through their EPS is low, with a rating of 49 (*ibid.*).

In these cases, listening centers, harm reduction programs, and community workers provide support to individuals who need assistance in obtaining their *cédulas*, registering for health insurance, and, when possible, registering with SISBEN.⁶⁷ In some municipalities—Pereira and Dosquebradas—individuals living in street situations must first obtain a special ID card issued by the governor's office and signed by the secretary of health in order to be able to get a *cédula*. Once this process is complete, and after the individual has registered with an EAPB from the subsidized regime, they may request an appointment with a general practitioner in order to be referred to a methadone program. In this appointment with the general practitioner, the patient is tested for HIV, hepatitis B and C, and syphilis. In some cities, a positive test result for any of these diseases

67 SISBEN (System for Selecting Beneficiaries of Social Programs) is a rating instrument that assesses the living conditions of individual families, with the aim of identifying beneficiaries of social assistance programs.

requires the patient to undergo appropriate treatment before being admitted to the methadone program. The entire process can take several months. Many times, the listening centers lose track of these individuals, who grow thin on patience after having to wait so long.

Before exploring access to treatment in the five selected cities, we wish to briefly highlight three life stories that reveal the suffering caused by the lack of essential controlled medicines for individuals living on the margins of society. These three narratives touch on individuals' experiences with heroin, with negligent health care services for pain treatment, and with the exhausting wait times that demand unrealistic levels of patience by individuals who are suffering.

Pipe

I've started treatment programs more than ten times. I was in jail for a while, and the worst part of my drug habit was after that, when I was alone and couldn't get treatment. Finally, I went to one program, and the withdrawal was horrible—for the first twenty-four hours they didn't give me methadone, and the air conditioning was on full blast, freezing. They gave me a ton of drugs—levomepromazine, haloperidol, Benadryl, and who knows what else—and I told them, "Let me out of here." I got out of there and was feeling desperate, because I was thinking about how they almost made me crazy. I was so jittery that in three weeks I spent 700,000 pesos [about US\$225] on alcohol, weed, and cocaine.

Luz

I've heard that in [other countries], the government actually gives heroin to addicts, and that seems good to me. But if they could just make methadone more accessible here, we would be much better off. Methadone keeps me from feeling sick and crampy, and marijuana lets me think. I'm going to try taking the two together to see if it will help me quit heroin.

Harold

The police caught me robbing a bolardo [a type of traffic barrier placed on sidewalks⁶⁸]. They sentenced me to forty-two months in prison, but I did thirty-eight in Honda [a nearby city] because it was the only place with room. The withdrawal was so bad, they didn't give me anything. I was so desperate I tried to slash my wrists. When I got out of there, I told myself I

68 These cement structures contain metal on the inside, which can be resold in the informal market.

was going to quit heroin, since I had spent all that time without even using a little. But then I found out that my girlfriend had died from pneumonia and I relapsed.

Pathway to Access in Armenia

The department of Quindío has three methadone programs with the cumulative capacity to attend to 300 patients: La Milagrosa Health Center (outpatient program), Filandia Mental Hospital (inpatient program in Filandia and outpatient program in Armenia), and El Prado Clinic. According to the Special Registry of Health Service Providers,⁶⁹ as of October 2018, only Filandia Mental Hospital's programs were accredited. We were able to secure interviews with staff from the first two facilities. In addition, Quindío has a drug addiction center (*centro de atención a la drogadicción*, or CAD), Fenacorsol, which does not dispense methadone because it lacks an accredited pharmacy but which makes the medicine available to patients through a partnership with Filandia Mental Hospital. This IPS does not appear in the Special Registry of Health Service Providers.

Furthermore, the municipal government of Armenia offers a listening center that operates under the Secretariat of Health's public health program. The center is based out of a mobile tent and offers harm reduction services, usually in the downtown area, including the delivery of hygienic injecting materials and advice for people who use drugs. The center's team includes a psychiatrist (who comes once a week), a nurse, two nurse's assistants, a social worker, and two administrative assistants.

In 2017, the listening center reached 300 people, mostly people living in street situations, as well as a few students. Some clients visit the center on a regular basis, while others are one-time visitors. In addition to running the tent, the listening center's team conducts street rounds to raise community awareness about the program. These street rounds are important, as many PWUD are reluctant to seek health services for fear of punishment or mistreatment. By referring clients to La Milagrosa Health Center, the listening center acts as a "hook" to connect individuals to treatment options.

69 In several cases, we found that the Special Registry of Health Service Providers was not updated. In other words, its list of accredited IPSs did not correspond with those IPSs that were actually operating as accredited facilities in the five cities. This means that the registry is not necessarily an accurate reflection of available services in each city.

All of these traits make it a low-threshold program, which means that its services tend to be more appealing to the target population.

Table 2
Methadone consumption and population
in Quindío, 2011–2015

	2011	2012	2013	2014	2015
Consumption of methadone HCL x 10 mg Presentation: bottle of 20 tablets	505 bottles	3,900 bottles	174 bottles	0 bottles	70 bottles
Consumption of methadone HCL x 40 mg Presentation: bottle of 20 tablets	5,135 bottles	6,560 bottles	7,868 bottles	3,546 bottles	5,447 bottles
Total population of Quindío	568,506				
Population of people who inject drugs in Armenia (2014)	1,850				
Number of methadone programs	3				

SOURCE: Prepared by the authors based on data from the National Narcotics Fund, the Colombian Observatory for Palliative Care, Colombia’s 2015 national heroin study, and field visits

The Fenacorsol drug addiction center, which has been running for more than ten years, has a large space for inpatient treatment, as well as a controversial history of treating drug dependence. It operates under the “therapeutic community” model, which, in the words of the program coordinator, previously relied on punishment, humiliation, and “hitting bottom” as treatment tools. Today, the center claims that it no longer uses this kind of abusive treatment and is changing its model of care toward one based on cognitive behavioral therapy, with an interdisciplinary team of doctors, nurses, psychologists, and social workers. The facility is an officially registered CAD, with a capacity for thirty inpatients, of whom 30% are people who use heroin. In order to enroll in Fenacorsol’s treatment program, patients must have a psychiatrist-issued referral from their EAPB. Alternatively, they may enter via emergency care, where doctors issue a referral for their transfer. In this pathway to treatment, it is not clear to what extent the patient’s informed consent is sought or obtained. Fenacorsol’s treatment program lasts for twelve months and is divided into

six levels of goal fulfillment; the final levels are linked to labor-insertion programs.

Meanwhile, Filandia Mental Hospital serves between eighty and one hundred patients in its two locations. To enter the treatment program, individuals must first consult with their hospital's social worker to ensure that they are enrolled with an EAPB. They then must visit their EAPB for an appointment with a general practitioner and various exams. Depending on the situation, they are then referred to an inpatient or outpatient program. In the hospital's Filandia location, where the inpatient program operates, hospitalization lasts for one month, and there are twenty-eight beds available. In the hospital's outpatient facility, located in Armenia, there are approximately seventy patients, many of whom have children and 98% of whom are men aged 20–28 who began using drugs at an early age and have a history of heavy consumption. To receive a methadone prescription lasting for several days, patients must pass a monthly test for three months in a row showing no traces of opioids. In both programs (inpatient and outpatient), care is provided by interdisciplinary teams. In the outpatient facility, a psychiatrist is on site every other week.

La Milagrosa Health Center is a first-level health facility run by Red-Salud Armenia, which is the municipality's public health provider, and it has an outpatient methadone program. The program's care team includes a nurse, a psychologist, and a social worker. Given that the program operates within a health center that provides many other types of care (such as vaccinations, pediatrics, and laboratory exams), the facility has had to facilitate dialogue between the general community and PWUD in order to avoid altercations. Most of the methadone program patients are unemployed young men without a high school diploma. Patients with jobs are able to take methadone home with them, with prior approval from the social worker and psychiatrist. According to the facility's website, the methadone program was transferred to Sur Hospital beginning October 1, 2018. Finally, El Prado Clinic is an IPS that specializes in mental health and offers a methadone treatment program. Its location—in the northern part of the city—makes it the least preferred option for patients, as the other two facilities are closer to where they tend to live. All of Armenia's methadone maintenance programs usually administer an initial dose of 20 mg, with subsequent adjustments made in accordance with the patient's needs.

Pathway to Access in Cali

Cali has two accredited methadone programs: one is run by the Fundar Colombia IPS and the other is a municipal-run program through the Pilsen Wellness Center IPS, which opened after we conducted fieldwork in the city. The program at Fundar is the most expensive compared to those other cities. In addition, Cali has other care facilities where psychiatrists prescribe methadone: ESE Centro, Hospital Psiquiátrico, and Ciclo Vital. Interviewees referenced another IPS—La Luz Foundation—but it does not have methadone.⁷⁰

Table 3
Methadone consumption and population
in Valle del Cauca, 2011–2015

	2011	2012	2013	2014	2015
Consumption of methadone HCL x 10 mg Presentation: bottle of 20 tablets	908 bottles	735 bottles	1,569 bottles	2,531 bottles	3,402 bottles
Consumption of methadone HCL x 40 mg Presentation: bottle of 20 tablets	195 bottles	318 bottles	827 bottles	1,330 bottles	1,845 bottles
Total population of Valle del Cauca	4,660,741				
Population of people who inject drugs in Cali (2014)	3,501				
Number of methadone programs	1				

SOURCE: Prepared by the authors based on data from the National Narcotics Fund, the Colombian Observatory for Palliative Care, Colombia’s 2015 national heroin study, and field visits

In 2015, the Cambie project—a needle-exchange program run by Acción Técnica Social in Bogotá, Cali, Medellín, Pereira, Dosquebradas, and Santander de Quilichao—began operating by the nongovernmental organization Acción Técnica Social in collaboration with local community teams.⁷¹ Later on, the project was taken over by the mayor’s office of

70 An additional IPS—Basilía Clinic—was later added to the Special Registry of Health Service Providers; it was not in the registry at the time of our visit.

71 See “3ra entrega Cali – Especial CMBIE Colombia”: <https://youtu.be/LL-rkmorqFM4>.

Cali and is now known as the Risk and Harm Reduction Program.⁷² Its facility is located in downtown Cali, not far from Calle del H, the city's main heroin consumption point. Its facilities provide clients with hygienic injecting materials, advice, crisis and overdose care, and support during the path toward treatment. In addition, in 2017, it launched a methadone maintenance program supported by the mayor's office and the National Narcotics Fund and operated by Centro IPS. In 2018, due to the administrative difficulties involved in operating with a public IPS, the program began partnering with Pilsen Wellness Center IPS, which has twenty-five available spaces for treatment. Besides administering methadone, this program also provides psychological care and occupational therapy.

Meanwhile, Fundar Colombia has been operating since 2009 and embraces a bio-psycho-social-spiritual model of care that is implemented by a team whose members include a psychiatrist, a physician, an occupational therapist, and nurses. The high-threshold program—inpatient treatment—serves up to thirty people. Its methadone therapy services offer the option of total or partial abstinence. At first, patients are dispensed daily doses of methadone; after ninety days, they receive multi-doses that they can take home with them. On average, the programs last six months.

The Hospital Psiquiátrico also provides services for people who use heroin, but it has difficulties meeting demand since it attends to the mental health needs of all of southwest Colombia. In general, the drug dependence treatment program provides care for fifteen patients each month, who, in order to enroll, must have a support network; in practice, this requirement means that individuals who are in street situations are unlikely to be admitted because they generally lack supportive environments. It is worth noting that this hospital does not provide methadone as part of emergency room care, which means that people who use heroin and who enter the emergency room are forced to endure withdrawal symptoms. With regard to the methadone dose, the initial dose is 30 mg or less, and subsequent doses are 40 mg, with the dose eventually stabilizing at 40–80 mg.

72 According to officials from the National Narcotics Fund, this municipal-funded program is one of the most structured programs in the country due to, among other things, the continuity that it has enjoyed over time.

Pathway to Access in Cúcuta

In Cúcuta, the Consentidos Listening Center⁷³ plays a key role in supporting individuals in their pathways to treatment.⁷⁴ It is located along Bogotá Canal, a key consumption point in the city, where many homeless people also live. Center staff conduct street rounds each night, including on weekends and holidays, in order to provide hygienic injecting materials to PWUD.⁷⁵

Table 4
Methadone consumption and population
in Norte de Santander, 2011–2015

	2011	2012	2013	2014	2015
Consumption of methadone HCL x 10 mg Presentation: bottle of 20 tablets	1,048 bottles	888 bottles	834 bottles	376 bottles	319 bottles
Consumption of methadone HCL x 40 mg Presentation: bottle of 20 tablets	610 bottles	736 bottles	1,132 bottles	1,330 bottles	964 bottles
Total population of Norte de Santander	1,367,708				
Population of people who inject drugs in Cúcuta (2014)	2,006				
Number of methadone programs	1				

SOURCE: Prepared by the authors based on data from the National Narcotics Fund, the Colombian Observatory for Palliative Care, Colombia’s 2015 national heroin study, and field visits

Cúcuta’s only authorized methadone program is in the Rudensindo Soto Mental Hospital. It has been in operation for three years and has just thirty-two spots despite a much larger demand, meaning that there

73 Consentidos is a nongovernmental organization that has been able to operate a listening center thanks to occasional financial and technical support from the local mayor’s office and from national-level institutions such as the Ministry of Health and the Ministry of Justice.

74 The Cambie project did not operate in Cúcuta. The Consentidos Listening Center is a local initiative.

75 At the time of writing, the needle-exchange program had been discontinued.

is a long waiting list. Interviewees referred to other facilities that dispense methadone in rural areas and neighboring municipalities, but these facilities are not accredited.

There are two parallel routes in Cúcuta for accessing health care: the mental health route and the physical health route. The physical health route, which involves health centers, is used for anything that does not have to do with psychoactive substances, although some cases of illness treated in these centers are derived from the consumption of these drugs. Meanwhile, patients following the mental health route must first be evaluated by a general practitioner, then referred to the Rudensindo Soto Mental Hospital for exams and assessments, and then back to a general practitioner in order to receive a referral for treatment. Several interviewees explained that this process is very long and that sometimes patients are unable to wait. Some time ago, the Stella Maris CAD was also accredited to dispense methadone; however, this center is no longer in operation due to the difficulties in complying with accreditation requirements.

The Rudensindo Soto Mental Hospital has both an inpatient program and an outpatient one. Both programs have the same entrance requirements, with months-long waiting lists. For both programs, patients must first be hospitalized for a few days in order to undergo detoxification. If they screen positive for HIV or hepatitis B or C, they must bring a certificate from the infectious disease department confirming that they are undergoing treatment; without this certificate, they may not enter the methadone program. The hospital has thirty-two hospital beds for the inpatient program, and in October 2017 it had thirty-eight people participating in its outpatient program. The length of treatment depends on the patient, how well they adhere to the program, the length of abstinence, and how well the patient handles lowered methadone doses, which is a priority for the psychiatrist.

Patients' access to methadone outside the hospital is restricted, with exceptions granted only in certain cases, such as travel or work schedules. Methadone is dispensed every day, including holidays, at two different times. Patients are required to ingest the prescribed dose immediately upon dispensation. Health workers dissolve the pill in a glass of water, which patients may drink only once the pill has completely dissolved; the hospital takes this approach in order to prevent patients from reselling any remaining portions on the black market. According to the nurses at the hospital, the maximum dose is 40 mg.

Pathway to Access in Pereira

In Pereira, the Cambie project ran for four years, operated by nongovernmental organization Teméride as part of its care program for people in street situations.⁷⁶ Thereafter, in 2016, the National Fund for Development Projects and ESE Salud Pereira began running a needle-exchange program. During a transition period following Cambie’s closure, the municipal government and the National Narcotics Fund financed the launch of a day center for people who use drugs. All of these initiatives have been harm reduction efforts focused on providing hygienic injecting materials and condoms, as well as supporting clients in their paperwork for *cédulas*, enrollment in the health system, and pathways to treatment.

Moreover, Pereira has a unique status as a city-region together with Dosquebradas, where there is also a significant population of people who use heroin and where harm reduction programs also operate.

Table 5
Methadone consumption and population
in Risaralda, 2011–2015

	2011	2012	2013	2014	2015
Methadone HCL x 10 mg Presentation: bottle of 20 tablets	1,596 bottles	954 bottles	1,753 bottles	1,285 bottles	1,565 bottles
Methadone HCL x 40 mg Presentation: bottle of 20 tablets	1,015 bottles	1,901 bottles	2,459 bottles	2,935 bottles	2,288 bottles
Total population of Risaralda	957,254				
Population of people who inject drugs in Pereira (2014)	2,442				
Number of methadone programs	2				

SOURCE: Prepared by the authors based on data from the National Narcotics Fund, the Colombian Observatory for Palliative Care, Colombia’s 2015 national heroin study, and field visits

Pereira has two methadone programs: one at the Risaralda CAD in the Risaralda Mental Hospital and the other at the Psico Salud y

76 See “1ra entrega Pereira y Dosquebradas – Especial CAMBIE Colombia”: <https://youtu.be/oSsgu59j1bw>.

Transformación IPS. The Risaralda Mental Hospital is the only facility that appears in the Special Registry of Health Service Providers.

The Risaralda CAD, whose facilities are located within the Risaralda Mental Hospital, runs both an outpatient and inpatient program, and its model for care is determined according to the patient's needs. In February 2018, it had 170 patients, of whom 141 were in the methadone program. Most of the CAD's patients are young men. Many of those who access its services do so with the help of harm reduction programs, especially *Teméride*, which assists individuals with their *cédula* applications and enrollment in the health system. Three to four new patients enter the program each week. Care is provided by an interdisciplinary team that includes a psychologist, a nurse, and a social worker. To the extent possible, the Risaralda CAD encourages the involvement of the patient's family. The facility is located in the extreme south of the city, on the highway to Cartago. For many potential patients, the associated transportation costs are thus a barrier to accessing treatment.

The Psico Salud y Transformación IPS has been treating drug use disorders for ten years. It has the capacity to care for thirty patients, with half of these spots reserved for people who inject drugs. Its methadone program is a year-long inpatient program. Most patients are men between the ages of nineteen and twenty-seven who lack a high school diploma and come from low-income households, almost entirely single-parent families. Many of them live with HIV or have had hepatitis at some point during their history of drug use. To access treatment at this IPS, patients must undergo a process with their EAPB similar to that outlined earlier.

In both of these facilities, patients begin with an initial dose of 40 mg, which is subsequently adjusted according to their needs.

Pathway to Access in Santander de Quilichao

Although the size of the Santander de Quilichao's heroin-using population is unknown, the need for a health-related response for this population is evident.⁷⁷ An initial outreach effort was undertaken in 2017 by the Ministry of Justice—via the nongovernmental organization *Acción Técnica Social*—to survey this population, to propose a public health response to the issue, and to train local authorities on harm reduction interventions. Although this process generated great expectations among PWUD, their

77 See “5ta entrega Santander de Quilichao – Especial CAMBIE Colombia”: <https://youtu.be/SKuSt1qMn3c>.

families, and programs that work on this issue, to date it has not led to the rollout of any care program based on the study’s results. It is worth highlighting that the vast majority of people who use heroin in Santander de Quilichao do so through smoking or inhalation, not injection, which means that the provision of hygienic injecting materials is not a priority. Nonetheless, the lack of community-based programming and referral centers impedes individuals’ access to health services, as they have nowhere to turn to for support in their pathway toward treatment.

Table 6
Methadone consumption and population
in Cauca, 2011-2015

	2011	2012	2013	2014	2015
Methadone HCL x 10 mg Presentation: bottle of 20 tablets	130 bottles	413 bottles	201 bottles	537 bottles	766 bottles
Methadone HCL x 40 mg Presentation: bottle of 20 tablets	100 bottles	120 bottles	95 bottles	312 bottles	630 bottles
Total population of Cauca	1,391,836				
Population of people who inject drugs in Santander de Quilichao (2014)	No data				
Number of methadone programs	1				

SOURCE: Prepared by the authors based on data from the National Narcotics Fund, the Colombian Observatory for Palliative Care, Colombia’s 2015 national heroin study, and field visits

Prior to the 2017 study, the Francisco de Paula Santander Hospital had already been offering methadone maintenance therapy for three years, under various care models:

- Early intervention: for at-risk youth
- Day center: outpatient services for youth who use drugs and who lack a support network
- Outpatient: services for youth who use drugs and who have to work
- Low threshold: for individuals who have already tried several options and now seek to quit heroin via methadone therapy

- Inpatient care at a ranch: for people who, according to a psychiatric evaluation, should be hospitalized and treated with methadone for detoxification or maintenance

Although Santander de Quilichao lacks data on the size of its heroin-using population, according to the program coordinator at the Francisco de Paula Santander Hospital, 380 individuals receive drug dependence treatment each year; of these, 75% are people who use heroin, mostly men aged fifteen to forty-five who are out of school and informally employed, and many with criminal records. The hospital's inpatient program lasts for six months, after which point clients receive outpatient care. In addition, there is a rehabilitation center in Tunia, a small town in the municipality of Piendamó located forty minutes from Santander de Quilichao, which provides care for people from neighboring municipalities. This center dispenses methadone even though it is not accredited, and it treats withdrawal syndrome with a mixture of methadone (25 mg) and vitamin B complex. Neither of the two programs—Francisco de Paula Santander Hospital or the center in Tunia—appears in the Special Registry of Health Service Providers.

Barriers to Accessing Health Services and Their Impact on the Human Rights of PWUD

Colombia's Advisory Commission on Drug Policy has called attention to the need to design drug policies in a way that allows them to be implemented in accordance with the local realities and needs of locations where problematic drug use is present (Comisión Asesora para la Política de Drogas en Colombia 2015, 11). However, the local-level implementation of national policies continues to be a significant challenge.

As we will demonstrate in the last part of this chapter, the national government (namely the Ministry of Health and the Ministry of Justice), civil society, and certain local authorities, with the support of foreign development agencies, have made efforts to address the problematic use of heroin from a harm reduction perspective, just as proposed in national policies. These harm reduction initiatives have facilitated direct contact with the heroin-using population, sought to meet this population's most immediate needs, and, above all, provided a mechanism to facilitate individuals' access to voluntary treatment.

In terms of access to drug dependence treatment at the local level, the most recent information available is the Ministry of Health's survey entitled *Evaluation and Situational Diagnosis of Treatment Services for Users of Psychoactive Substances in Colombia: 2016*. The ministry analyzed various databases and information sources to identify 181 institutions that offer care and treatment for individuals who use psychoactive drugs, among whom it then conducted a survey. The institutions included in this list offer one or more of the following services: hospitalization, partial hospitalization during the day or night, outpatient care of low or medium complexity, and nonhospital confinement (i.e., residential care) (Ministerio de Salud y Protección Social 2016).

The study found that nearly 66% of the institutions that offer these services are either in Bogotá or in one of five departments (Antioquia, Valle del Cauca, Atlántico, Quindío, and Cundinamarca). At least nine of Colombia's thirty-two departments lack such facilities altogether, meaning that people with drug use disorders who wish to access such services need to travel to another department to get it—and their EAPB needs to have a coverage agreement with the IPSs in the other department. With regard to the departments studied in this book, Valle del Cauca and Quindío have the largest percentage of such facilities, with close to 8% each, followed by Cauca (4%), Risaralda (3%), and Norte de Santander (1.2%). These figures are worrisome if we keep in mind that 20% of such facilities are in Bogotá—in other words, the IPSs that offer these services are concentrated largely in Bogotá compared to other cities (*ibid.*).

Moreover, of the twenty-three departments that do have such facilities, 50% have fewer than five IPSs that provide care, and the majority of them are in capital cities. “The supply of specialized treatment for people with psychoactive substance use disorder is nonexistent in nearly 95% of the country's 1,122 municipalities” (*ibid.*, 94).

Although there is a correlation between, on the one hand, departments and cities with greater prevalence of psychoactive drug use and, on the other, areas with a greater supply of treatment programs (Bogotá, Antioquia, Valle del Cauca, and Quindío), there are some departments with a high prevalence of drug use that do not have a reasonable supply of relevant services (e.g., Meta, Nariño, Norte de Santander, and Risaralda) (*ibid.*).

According to the Ministry of Health, most of these facilities are private, and nearly 60% are registered as nonprofit entities, especially foundations, associations, and religious organizations. In terms of their

treatment models, although the clinical-psychological approach has increased in comparison to a survey conducted in 2004, the twelve-step and therapeutic community models continue to be the most widely used (ibid.). Furthermore, just 20% of the institutions surveyed in 2016 provide emergency care for people experiencing psychoactive drug poisoning or overdose. Although there has been a 20% increase in the number of institutions that offer such care compared to the 2004 survey, most of these facilities are located in three capital cities (ibid.).

Based on this analysis, we can conclude that there remains a significant shortage of evidence-based treatment programs for psychoactive substance use disorder, even if there is no established standard for the minimum number of institutions necessary to meet demand. The results of our fieldwork, which revealed long waiting lists for many of these programs, also suggest that the available programs are not enough. Additionally, there is no consolidated information on the quantity or quality of specialized treatment programs for people who use heroin. We can therefore conclude that despite the existence of a broad legal and policy framework on the issue, critical hurdles continue to impede this population's effective enjoyment of the right to health.

This institutional and social panorama also reveals that barriers to access are related to service quality, physical accessibility, and affordability, since even though these services are included in the Health Benefits Plan, patients are often forced to resort to filing *tutelas* (writs of constitutional protection) or pay out of pocket. As we showed in chapter one, evidence-based treatment for heroin use disorder exists and includes methadone maintenance therapy, as well as comprehensive psychosocial care. However, our research revealed that access to this treatment is riddled with obstacles stemming from the health system's inability to respond to the realities of this population.

Not only are people who use heroin involved in illegality and subject to societal stigma, but they also have very little voice compared to other populations, given that they tend to lack support networks, economic power, and the ability to advocate for their health needs. They are also required to abide by the often excessive rules of methadone programs, including dressing in a certain way, not being able to share food with others, and not being able to receive visitors. Methadone maintenance programs also frequently impose onerous conditions on patients, such as requiring them to fill their prescriptions on a daily basis for several months, and

conditioning care on compliance with other treatment in cases of comorbidities, such as HIV and hepatitis B and C. The power dynamics are such that certain actors—particularly health professionals—set and enforce the rules and, ultimately, patients' way of life. Among this population, there is thus a significant level of resistance toward medical professionals in light of their arrogance and condescension toward PWUD.

What is more, fear and the threat of punishment consume a great deal of personal energy, particularly in the areas of the brain responsible for self-control and abstract reasoning (Szalavitz 2016, 6, 58). During our fieldwork, we learned of cases in which the very drug used for treatment is brandished as a form of punishment: if patients arrive late to their appointment, or if they are found to have consumed another substance, they are denied their methadone dose.

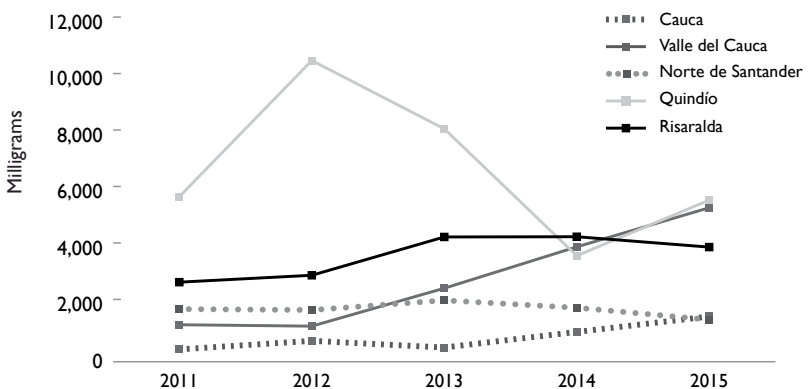
Police repression and persecution not only threaten PWUD with incarceration and harassment but also have practical effects on these individuals' behaviors. When police conduct raids and other interventions in *ollas*, those who suffer the most are people who use heroin, since the drug becomes impossible to obtain in the days immediately following the raid in light of the heavy police presence. The community workers we interviewed told us that during their street rounds following such raids, they find these individuals suffering from withdrawal syndrome. In addition, the police treat this population as a threat to citizen security instead of considering their health needs. As the mother of one patient told us, "Once, when he was stabbed with a machete, they took him to the emergency room, and he was arrested right there by the police. They took him to prison and he was beaten."

Police also frequently confiscate hygienic injecting materials, even when they know that such materials are provided by government-funded harm reduction programs. Individuals living in street situations are also often mistreated physically and verbally by officers. Furthermore, although harm reduction programs conduct sensitization training for police officers in neighborhoods where drug consumption is concentrated, when homeless individuals who use drugs migrate to a different neighborhood, they must deal with police officers who have not had such training.

Opioid maintenance therapy has many detractors and is highly stigmatized, both among health professionals and among patients and their families. Many of the people we spoke with characterized such treatment as "replacing one addiction with another," but this perception overlooks

several key aspects of drug dependence. First, a drug use disorder is not only about substances being consumed but also about patterns of learned behavior. Szalavitz captures this phenomenon aptly when describing professor Timothy Leary’s concept of “set and setting”—in other words, one’s frame of mind and the environment in which drug use takes place. These factors are what influence a person’s pattern of drug use, which is usually irregular because it depends on whether the person has money and access to a dealer (Szalavitz 2016, 126–7). When this kind of irregular consumption is replaced with a steady, stable supply that is administered at the same place and time, the individual achieves a plateau of tolerance that allows for other psychosocial interventions to take place in support of recovery. In addition, with the proper dosing, methadone does not cause a “high” or an emotional “block,” meaning that individuals can carry on with normal daily activities, since they are not “high” (ibid., 130–1).

Figure 4
Methadone consumption (milligrams), by department



SOURCE: Prepared by the authors based on data from the Colombian Observatory for Palliative Care

The dose used in maintenance therapy should be determined by a trained professional; and in order for it to successfully stabilize the person’s brain functions and decrease cravings and withdrawal symptoms, it should generally be administered for more than six months (World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS 2004, 12). Despite the dearth of methadone services in the five

cities studied here, these cities have seen a slight increase in methadone use in recent years, as illustrated in the following graphic.⁷⁸

The barriers that we identified with regard to access to methadone treatment can be divided into four categories, in accordance with their structural cause: (i) drug control measures; (ii) health system barriers; (iii) lack of training among health professionals on psychoactive substance use disorders; and (iv) stigma toward PWUD and drug dependence treatment.

Most of these barriers are present in each of the five cities, for they derive from social norms and practices common throughout the country in terms of the right to health, particularly for PWUD. Further, some of these hurdles are interrelated—for example, stigma toward PWUD leads to reluctance and refusal to treat these patients for other health issues unrelated to drug use.

Drug Control Measures

The fact that treatment for heroin use disorder requires a controlled medicine such as methadone means difficulties in ensuring the medicine's availability and accessibility, for regulations are often onerously written or excessively enforced.

In terms of medicine shortages, in several of the cities, employees of the IPSs with methadone programs told us that such shortages can occur for long durations, which forces patients to turn to the illegal market. For example, in Cúcuta, methadone was once unavailable for three months. Further, during a prolonged methadone shortage, individuals' risk of a relapse is very high—this was the case in Pereira in 2012, when a year-long shortage arguably caused many patients to “fall off the wagon.” Not all IPSs have this problem, though; in fact, some indicated that they have never experienced shortages because they plan their purchases in such a way that they always have a reserve on hand. But when we asked the Regional Narcotics Funds about shortages—not just of methadone but of opioids in general—most stated that such occurrences were rare and that when they did occur, they were due largely to delays in the National Narcotics Fund's purchase and delivery process. It is worth noting that the Regional Narcotics Funds, when calculating how many opioid medicines to obtain in a given year, use the average number of IPS sales from the

78 It is not possible to establish how much of this use is for maintenance therapy or pain treatment.

previous year, which is a problematic approach because such sales do not accurately reflect demand.

It is also important to highlight that only those IPSs with sufficient financial resources are able to purchase opioid reserves, which is the case only when their affiliated EAPBs are prompt with payments. As we will see later, not all IPSs have this luxury, which prevents them from considering this option.

As we will explore in chapter three, the IPSs that provide methadone treatment and are accredited to dispense the medicine purchase it from Regional Narcotics Funds or authorized pharmacies. They generally buy methadone once a year, in the amount required for the following year; however, the EAPBs pay the IPSs only after that new year has concluded. This means that IPSs must pay up front for the medicines and services offered to EAPB patients—and such costs tend to be high, especially considering that methadone is an imported drug.

Medicine shortages can also result from purchase orders that fail to meet a department's demand. As discussed in the next chapter, methadone is used not just for heroin dependence treatment but also for pain management and relief for end-of-life patients. However, as doctors who treat PWUD explained to us, department-level purchases of methadone have not increased in order to meet both of these needs. When we analyzed Regional Narcotics Funds' processes for calculating opioid need and for purchasing these medicines, it was evident that these processes fail to consider epidemiological studies that allow for accurate estimates of the need for opioid medicines in a given area.

In terms of pharmaceutical dispensation of opioid medicines, there are a number of challenges stemming from restrictive regulations, as well as from the erroneous interpretation of these regulations. Each department has its own type of prescription pad for these medicines, which impedes access for patients coming from other departments. This problem is particularly conspicuous in neighboring cities from two different departments and that share patient populations, such as Cali (located in Valle del Cauca) and Santander de Quilichao (located in Cauca). Someone who lives Santander de Quilichao and travels to Cali for care will receive a prescription written on the letterhead of the government of Valle del Cauca, but they will need to fill their medication in their city of residence, which is in Cauca. Although the National Narcotics Fund allows for controlled medicines to be dispensed in a department other than the one where the

medicines are prescribed, we learned of many cases in which pharmacies do not follow this rule.

Nowhere does the relevant standard (Resolution 1478) indicate that a prescription from one department cannot be filled in another; nevertheless, pharmaceutical establishments often interpret this standard more strictly than they should and refuse to dispense controlled medicines when the prescription comes from another department. To fill a prescription, the patient must provide three versions of the prescription—one original and two copies—for the pharmacy, the EAPB, and the patient. Sometimes, however, the departmental government runs out of official prescription pads, leaving physicians unable to write prescriptions. These hurdles can be easily overcome when dealing with officials from Regional Narcotics Funds and pharmacists who understand that this shortcoming is due to the departmental authority's failure to print a sufficient number of prescription pads and thus allow prescriptions to be written on the physician's personal prescription pad in the meantime. However, other personnel sometimes cling to the letter of the law, forcing patients to go without opioids for as long as the department is out of prescription paper. This constitutes a serious violation of this population's right to health.

While the regulation on controlled medicines notes that any physician can prescribe opioids, in practice, only psychiatrists—and among them, just a few—tend to prescribe methadone to people who use heroin. As discussed below, this is due both to a lack of training among physicians and to a misguided interpretation of the regulation.

Cities such as Cali, which have sufficient institutional capacity and political will to offer a methadone program, encounter a barrier in which municipalities lack the autonomy to purchase medicines directly from the National Narcotics Fund. And although the option of purchasing from third- and fourth-level hospitals exists, this option is not very well known or utilized.

Finally, at the administrative level within Regional Narcotics Funds, changes in governorships sometimes generate unwanted and confusing adjustments in processes that can interfere with the funds' purchasing processes before the National Narcotics Fund.

Health System Barriers

Low-threshold treatments, which are the ones most likely to generate the target population's trust and to protect their rights, generally suffer from a

lack of funding and personnel. Further, these programs do not enjoy total continuity in many cities. These programs successfully help individuals change their behavior and prevent infections and other health problems, but this progress risks being lost the moment patients transition from these programs to other ones, as the low-threshold services are unable to ensure continuity of services.

Another key hurdle is the fact that first-level health facilities offer few mental health services or services for substance use disorders.⁷⁹ These facilities are the ones most likely to be visited by people who use drugs, but at most, they provide patients with general health care aimed at their overall physical health. Mental and physical health care are offered separately (exams required for entrance into detoxification programs are performed in other health centers), which makes it hard for patients to adhere to treatment since they must deal with numerous bureaucratic obstacles in order to be admitted. Other factors that affect individuals' adherence to treatment are suboptimal doses of methadone, the strict rules of treatment centers,⁸⁰ geographic barriers, and the lack of good-quality comprehensive care, among others.

In many cases, people who use drugs are unaware of their right to treatment. In Cali, for example, we met a young man who had been purchasing methadone illegally in order to adhere to his treatment plan—he didn't know that his EAPB was obligated to provide the medicine to him. In all five cities, listening centers and harm reduction programs play a vital role in raising people's awareness of their right to voluntary treatment.

The care models embraced by most IPSs also fail to take into account the realities of the population. The locations where IPSs dispense methadone are often far from neighborhoods where PWUD live and use drugs, which can make it hard for people to continue treatment because they cannot afford transportation.

In Cali and Armenia, we also found that some EAPBs that lack affiliations with methadone programs prescribe the medicine on a monthly basis, without offering additional support to the patient. Such practices operate as diversion points toward the black market, as some patients sell half or all of their prescribed dose.

79 Cali and Armenia are exceptions in this regard.

80 For example, requiring that individuals exercise abstinence from all other substances and conform to the center's limited operating schedule.

This represents a shortcoming in the care model, for interventions aimed at drug use disorder, as explained above, should go beyond substance use and address the emotional, psychosocial, and economic aspects of the patient's life that precipitate the problematic use of drugs. Instead, by simply handing the patient a monthly prescription—consisting of one or two bottles of methadone pills—EAPBs are providing a medicine without treating the structural causes behind the person's problematic drug use.

That said, the illegal drug market plays an important role for the population—or, in the words of a psychiatrist we interviewed, “The black market, in light of the shortcomings at the administrative level, is not that bad.” Given the few available services, EAPBs' lack of sufficient affiliations with specialized IPSs, and the cumbersome bureaucracy involved in accessing treatment, purchasing methadone in the illegal market is a practical alternative for self-administering one's own detoxification or maintenance therapy.

By no means are we suggesting that self-prescribed “treatment” is an ideal solution; we are simply acknowledging that given the health system's serious failings vis-à-vis this population, there are times when a methadone pill purchased in the illegal market can alleviate anxieties that otherwise have no solution. This was the case for the mother of a PWUD in Santander de Quilichao, who told us that it was so difficult for her son to secure a spot in a treatment program that she was resorting to the black market to buy methadone and alleviate his withdrawal symptoms, allowing him to sleep calmly at night.

A young man in Cali told us that his EAPB prescribes him six bottles of methadone each month and that he keeps two and sells the rest on the black market at a lower price than what is offered in pharmacies. His situation sheds light on a poor practice on the part of EAPBs and the physicians who prescribe controlled medicines in this manner. On the street, the average price of a bottle of twenty tablets in Cali is 90,000–170,000 Colombian pesos (about US\$29–54), while in Cúcuta a 40 mg pill costs 15,000–20,000 Colombian pesos (about US\$4–6). When prescription methadone is in short supply, prices in the black market rise—and even there, this medicine can run out.

In the Colombian health system, someone who needs to switch EAPBs is temporarily left in a limbo, for during the month in which the transfer takes place, the person is allowed to access only emergency care.

For people who use heroin, changing EAPBs—for whatever reason—means automatically being discharged from their methadone program, which potentially increases their change of relapse, with all the health risks it implies, including the risk of a lethal overdose. A person might need to change EAPBs, for example, after securing employment, as this would require them to move from the subsidized regime to the contributory one, leaving them without treatment for an entire month. In such cases, the secretariat of health should cover treatment for the month in which the transfer takes place.

This situation is further aggravated when EAPBs have outstanding debts with IPSs hired to provide medicines, which implies constant financial risks and can lead to closures of clinics due to EAPBs' failure to pay. In such situations, governmental oversight of the health sector is insufficient to ensure compliance with rules and payment agreements. In many cases, IPSs give up after several rounds of negotiations and the lack of payment for two or more years of services, finally deciding to end their affiliation with that insurer. Such scenarios leave patients adrift, since if their insurer no longer has an affiliation with a methadone program, there is nowhere to go for treatment. When agreements fall apart in this way, patients undergoing treatment can get “lost.” In some cases, patients file *tutelas* that eventually permit them to access methadone treatment even when their EAPB has no affiliated provider.

The EAPBs see controlled medicines as difficult to obtain and administer. Indeed, the fact that these medicines are controlled means that they must undergo additional steps prior to being purchased and dispensed; however, EAPBs should not use this as an excuse to avoid securing the pharmaceutical services necessary to ensure the availability of opioids, as they are legally obligated to do so as part of the guarantee of the right to health. In addition, EAPBs authorize only up to one month of hospitalization for such treatment, which is not enough for some patients—not just in terms of treatment but also because they have no home to go home to.

Health Professionals' Lack of Training on Psychoactive Substance Use Disorders

In Colombia, medical school training generally places little emphasis on mental health issues, especially treatments for substance use disorders. This is partly due to the fact that Law 1566 is relatively recent, and prior to its passage, treatment for drug dependence was not part of the country's

obligatory health package. Thus, the health system provided little incentive for health practitioners to develop expertise in a field that could not be billed to the EAPBs. As a result, today there are few health professionals with adequate knowledge in the area.

Added to this lack of mental health training is a mixture of moral and personal prejudices among health professionals in which PWUD are considered “difficult” and methadone is seen merely as “replacing one addiction with another,” as described by several interviewees. In particular, physicians’ lack of awareness of withdrawal symptoms and how to treat them is concerning, as this ignorance triggers serious suffering among PWUD at all levels of health care. As one young man explained to us regarding his emergency room experience, “A few years back, I had an overdose and they brought me to the hospital, but they didn’t give me methadone because they didn’t even know what was happening to me. So I ripped off my IV and got the hell out of there.”

In terms of treatment, we found that methadone is frequently administered in inadequate doses due to this same lack of training among physicians, which not only causes patients to continue suffering withdrawal symptoms but also fails to fulfill the purpose of “maintenance.” One tragic example of this is the case of Susana, a forty-year-old woman from Cali with a twenty-year history of heroin use. She told us that she once spent two years in Bogotá for methadone treatment, where it was going well. Upon her return to Cali, she was hospitalized, and the attending physician radically decreased her daily dose—from 110 mg to 40 mg—which caused her to abandon treatment in light of the withdrawal symptoms she began to experience. Susana also told us how during a subsequent detoxification process, she received clonazepam instead of methadone,⁸¹ and then during the treatment portion, she received methadone. We learned a few months later that Susana had passed away.

Stigma toward PWUD and Drug Dependence Treatment

As explained to us by a community worker, people who use drugs are stigmatized according to the substance they consume, and they are re-stigmatized if they relapse after completing a treatment program. At a practical level, stigma against this population occurs on two fronts. First,

81 According to clinical guidelines outlined by the World Health Organization, standard treatment includes an opioid. Because clonazepam is not an opioid, giving Susana clonazepam was not sound clinical practice.

it takes place in the delivery of health care that is unrelated to drug use. As the mother of a patient told us, “One day, my son was taken to the emergency room because he was very ill, and the doctor said they would treat the other patients first because he was just another drug addict with a lot of drama.” Second, stigma shapes drug dependence treatment programs, which are often influenced by certain moral and social prejudices.

With regard to general health care, one recurrent problem we encountered in all five cities is the discrimination that PWUD face when seeking non-drug-related health care, such as when they go to the emergency room for a wound, infection, or any other problem requiring urgent treatment. Generally, these individuals fail to receive the care they need because once they are hospitalized, their withdrawal symptoms become more acute and health personnel, in order to avoid dealing with the issue, pressure them to sign voluntary discharge papers. Meanwhile, the patients, feeling ill from withdrawal and not getting any medicine for it, sign the papers before receiving the primary health care that brought them there in the first place. This kind of discrimination means that many health conditions among PWUD become worse and that, in general, PWUD avoid seeking medical care.

This lack of medical care, besides being negligent, may also constitute cruel, inhuman, and degrading treatment and may threaten patients’ lives. We witnessed two cases—one in Cali and another in Cúcuta—in which young men with serious leg injuries, unable even to walk because of the pain, opted not to visit the emergency room because of the mistreatment, not to mention withdrawal syndrome, they knew awaited them. In any area of health care, situations such as these would be considered malpractice and ethically questionable departures from medical standards, but somehow the stigma underlying this type of behavior toward PWUD means that such situations pass unnoticed, with only those in the trenches of drug use able to recognize what is happening.

Those who are in the trenches—such as community workers from listening centers and people who work in harm reduction programs—are well aware of these tensions and have come up with clever ways to support PWUD during their emergency room visits. For example, they sometimes buy methadone pills on the black market and then accompany and give this methadone to patients during the seemingly interminable wait time before being attended. These workers save many lives this way, which has

convinced them of the need to sensitize primary care personnel on the use of these medicines.

With regard to treatment for psychoactive substance use disorders, we found that myths concerning methadone are the main barrier to access. Although physicians can prescribe methadone, they need training on its administration, and such training is scarce. As a result, practitioners frequently see methadone as just another addictive substance and not as a therapeutic aspect of treatment. One patient told us that she was denied methadone while enrolled in an inpatient treatment program, where health care personnel admonished her that it was just “another drug.” This woman, who has acquaintances who have successfully overcome heroin dependence, knows that they were able to do so as a result of treatments that include methadone. To be sure, methadone is a drug—but it is a drug that is not incapacitating, that allows the individual to function, and that therefore facilitates recovery.

One significant barrier to access is the fact that many patients are required to first undergo inpatient detoxification before commencing a methadone program. Asking these individuals to transition from a very unstructured life to hospitalization is not realistic, and, as a result, many quickly request voluntary discharge. Moreover, the wait times for methadone programs are extremely long due to the programs’ scarcity, and this carries great health risks, as explained by Nelson: “As I waited to be able to enter a detox program, I had heavy withdrawal symptoms, and someone helped me buy drugs. I used water from a stream to mix the powder, and when I injected, bacteria entered my veins and caused bacterial endocarditis that ate part of my heart.”

Furthermore, methadone programs have many rules, some regarding compliance and others concerning admission into the program. Concerning the former, programs’ design should take into account the time and travel required to access opioids needed for treatment, as well as the expenses, which patients inevitably compare with the cost of heroin. Out-patient programs require that patients have bus money on a daily basis, which can make it difficult for those who lack a steady source of income to attend as required. For this reason, some patients ask to be hospitalized, thus simultaneously resolving their health, living, and income problems. But this solution is not a long-term one.

The rules in methadone programs are sometimes inordinately strict, such as with regard to the hours during which patients can claim their

daily prescriptions. Program operators are often unsympathetic to patients' situations and lives, instead reinforcing existing stereotypes about PWUD. For example, one administrator from a methadone program explained that "it doesn't matter what business hours you set, they're never going to comply, and dispensing medicine all day long is just encouraging [drug] use." According to this interviewee, patients do not respect operating hours and arrive late because they are "shooting up" before coming for their daily dose. Indeed, this could very well be true, but in that case, it would be necessary to review the doses being prescribed to see whether patients' decision to use heroin is to compensate for an insufficient methadone dose.

In this particular case, the program's operating hours used to be 1–3 p.m., which catered to the daily routines of PWUD but which was not convenient for the program's administrators, who are supposed to dedicate their afternoons to filling out medicine consumption reports. It is worth finding out whether these reports are required by health authorities or whether they are internal program procedures. Regardless, a health care program's priority should be to offer medical care in the manner that best meets patients' needs. In the words of a patient's mother, "If you don't have a prescription or if you arrive late, there's no methadone for you that day." It is clear that strict and sometimes arbitrary rules like these place patients at risk of not receiving treatment, which can have a particularly negative impact on patients' adherence to treatment.

With regard to rules concerning admission into treatment programs, many facilities require that patients who screen positive for other illnesses, such as HIV and hepatitis B and C, first undergo treatment for those diseases. For example, we encountered one case in which a young woman from Cali had been trying for several months to get her EAPB to authorize methadone treatment, but the IPS refused to admit her into the program until she had first begun treatment for the hepatitis that had been detected in her screening—treatment that had been delayed for nearly a year due to the same EAPB's cumbersome procedures. It is imperative for the health system to prioritize windows of opportunity for people who wish to enter treatment programs, instead of causing patients to miss out because of red tape.

None of the harm reduction or methadone programs we visited stock naloxone, a vital medicine for reversing an opioid overdose and therefore saving lives. Although this drug is available in second- and third-level

hospitals, it is still not seen as part of the essential package of care for this population. It is important to consider, for example, stocking this medicine in ambulances and first-level emergency facilities, as well as health centers in areas where heroin use is prevalent, as these facilities are likely to be the ones that PWUD go to in case of an overdose. If this medicine is not available, the state is failing to guarantee the fundamental right to life.

For some people and their families, therapeutic communities seem like a good option, for they offer support, they remove the patient from drug-using environments, and they provide long-term residential settings. One mother we interviewed had been searching for more than two years for an affordable therapeutic community program that would take her son. As mentioned earlier, therapeutic communities are controversial due to the range of associated problems, such as a lack of regulatory oversight, claims of abuse, and their failure to rely on evidence-based treatments, such as methadone. One young man, who is now in a methadone program, told us that “these start-up foundations like Corazón Valiente and Jesucristo Hombre break you apart, they charge a ton, and people are brought there against their will.”

In general, treatment services lack a differentiated approach, and we found that some programs have a policy of not admitting women, claiming that “it can lead to complicated emotional relationships” between female and male patients. Moreover, many treatment strategies are based on mental and physical discipline that, according to the health personnel working in these facilities, would not be applicable to women who use drugs. Thus, there are no specific treatment programs for women, meaning that when a woman requests treatment, she may be referred directly to a psychiatric facility, where she is forced to share a setting with people who suffer from other kinds of mental disorders—a fact that ultimately disincentivizes women from seeking care. Trans individuals also face barriers to accessing treatment, since they usually reside in red-light districts, where turf wars can impede individuals’ mobility.

Finally, once a patient’s treatment comes to an end, there is often no follow-up. Outpatient methadone programs do not offer good psychosocial support, and inpatient programs do not ensure support networks once patients leave the hospital and are at risk of relapse.

In conclusion, it is important that harm reduction programs and methadone programs coordinate with each other. Nelson’s testimony speaks to this need, for he told us that he always went to the Cambie

program, where “they gave me everything, except for what I needed most: methadone.” The harm reduction program undoubtedly reduced risks for Nelson and protected him from many illnesses, but for someone who wishes to quit heroin, the most urgent need is quick and effective coordination that facilitates the pathway to treatment, as is their right.

Unfortunately, mistreatment of people who use drugs is all too common. We heard many stories about PWUD being denied medical treatment, even when visiting the emergency room for a serious injury, pneumonia, or other illness requiring urgent care. Physicians and nurses are frequently eager to offer these patients voluntary discharge, without first treating the health issue that brought them to the emergency room or the withdrawal symptoms they are suffering. Health professionals, who must abide by medical ethics and the principle of nondiscrimination, often fail to provide care for this population because it makes them uncomfortable. As explained by Liz Evans, a global leader in harm reduction, these people are treated harshly, even by those who have made a career out of compassion (Maté 2010, 11).

Let us imagine for a moment that the same “care” and “treatment” techniques and practices were being applied to someone suffering from a chronic disease, such as diabetes or high blood pressure. Imagine that this person’s treatment consisted of punishing his or her behavior and labelling them a liar, weak, and incompetent. This would be considered a blatant violation of medical ethics. But society and health practitioners who attend to PWUD frequently embrace this vision of punishment and humiliation. Why are we allowing this to happen?

We must not forget that most people who seek treatment are living on the streets and lack a support network. Support networks are community centers, listening centers, and harm reduction programs that accompany individuals in their pathways to treatment, but even in the best of situations, after completing methadone therapy, these individuals face barriers to accessing employment and housing that can put them at risk of relapse. In Pereira, for example, at the end of a street round that we accompanied, we stumbled upon a set of physical barricades; our guide explained to us that these barricades are used to close off the streets at night so PWUD cannot go downtown or to other areas. This type of daily violence pushes this population even further toward the margins.

CHAPTER 3

PAIN'S REVOLVING DOORS: THE DISTANT PROSPECT OF PALLIATIVE CARE

If there is a single dimension of illness that can teach us something valuable for our own lives, then it must be how to confront and respond to the fact that we will all die, each of us.
Arthur Kleinman, *The Illness Narratives* (1989, 157)

Providing comfort to someone at the end of life means offering solutions at a time when a cure is unrealistic. These solutions should be squarely linked to the patient's needs and wishes: they should provide the information needed by the patient to make decisions, as well as the support required by the patient and their loved ones. In most cases, death is not something that simply happens—rather, it is a process in which the goal is to execute the decisions that the patient is willing to make and to thus understand when to stop insisting on curative treatments. To accompany a patient at the end of life, as well as the loved ones who are involved in this process, it is important to engage in what Kleinman calls “empathetic witnessing”: allowing dialogue even if there are no answers to the difficult and mysterious questions surrounding death (Kleinman 1989, 154). Palliative care offers such possibilities, and opioid medicines are a crucial part of the picture, given that pain is one of the biggest concerns of patients and their families. If pain is not managed, it is hard for end-of-life decisions and conversations to take place.

Nonetheless, the end of life, which is a critical time for patients and their loved ones, is generally the moment when the field of medicine steps aside. This abandonment of a terminally ill patient stems from medical training, which is focused on “saving” but not accompanying someone to

the end. Modern medicine did not adopt this role as savior until after the Second World War. Prior to the war, hospitals were places where sick people received treatment and care, but not cures. With the emergence of antibiotics and other medical technologies, health professionals as we know them today are expected to save lives. This theoretical and practical model of medicine has not adapted to caring for patients who are suffering at the end of life, a role that family and religion used to fill (Gawande 2014, 70).

Palliative care offers a response to the physical, psychosocial, and spiritual problems of patients and their families during the end-of-life process. It is an interdisciplinary approach whose guiding principles center on providing patients with the best quality of life possible and guaranteeing their dignity until the very end. An essential element of palliative care is the management and treatment of pain with opioid medicines.⁸² However, given the excessive controls on these medicines within the framework of the international drug control system, many patients encounter hurdles when trying to obtain opioids.

This chapter explores the barriers to accessing opioid medicines for palliative care in the five cities studied in this book: Cali, Santander de Quilichao, Pereira, Armenia, and Cúcuta. The chapter is divided into four sections: The first discusses the demand for palliative care in Colombia based on demographic and epidemiological data and explores the extent to which such care is effective in providing comfort for and guaranteeing the right to health of patients. The second section describes the legal and policy framework through which Colombia has sought to address the need for palliative care. The third section, based on our interviews with key stakeholders, explores the status of palliative care in the five aforementioned cities. The fourth and final section outlines the barriers to accessing opioid medicines for palliative care.

The Need for Palliative Care in Colombia

There is no exact figure on the need for palliative care in Colombia, given that such care can potentially be used for a wide range of illnesses and populations. However, we can obtain a general idea through several proxy indicators: population ageing, noncommunicable diseases (including cancer), and mortality from these diseases.

82 See the World Health Organization's (2019) definition of palliative care.

Colombia's growing population of older persons, together with increased life expectancy, influences the demand for palliative care. According to data from the Economic Commission for Latin America and the Caribbean, Colombia's population aged sixty years and older is expected to nearly triple between 2010 and 2050: in 2010 this population represented 9% of the general population, in 2030 it will have increased to 18%, and in 2050 it will have increased to 27.4%. Meanwhile, life expectancy is on the rise: while in 1990–1995 it was 68.8 years, in 2016 it increased to 74.3 years, and for 2025 it is projected to increase to 76 years (Economic Commission for Latin America and the Caribbean 2017). This points to the need for Colombia's health system to make the necessary adjustments so that health care can be better positioned to address the needs of the elderly.⁸³ A first step in this direction would be for Colombia to ratify the Inter-American Convention on Protecting the Human Rights of Older Persons, which has specific provisions on the right to health of this population (Pereira-Arana 2016, 30).

For 2014, according to data from the Pan American Health Organization, noncommunicable diseases accounted for 48% of deaths among men and 71% of deaths among women. The leading causes of such deaths were cancer (34% for women and 17% for men), cardiovascular diseases (27% for women and 24% for men), diabetes (5% for women and 4% for men), and chronic respiratory diseases (4% for both sexes) (Pan American Health Organization and World Health Organization 2017). In addition, in 2018, Colombia was projected by the Global Cancer Observatory to have 46,057 cancer-related deaths, 101,893 new cancer cases, and a 17.99% risk of acquiring cancer before the age of 75 (International Agency for Research on Cancer 2018). In the five departments studied here, the total number of cancer-related deaths in 2014 was 9,866.⁸⁴

Given that people who suffer from these kinds of diseases will require access to palliative care and to medicines for pain relief, it is important to analyze the availability of these services and medicines in the country, especially the cities that are the focus of this book. According to the *Atlas of*

83 Older persons who require palliative care usually need it because of underlying diseases, such as Alzheimer's and dementia, not because of their age. However, many palliative care principles are relevant for elderly-related care (International Association for Hospice and Palliative Care 2019b).

84 Figure obtained from the National Cancer Information System. See www.infocancer.co.

Table 7
Estimated need for palliative care and a summary of existing services in Cauca, Norte de Santander, Quindío, Risaralda, and Valle del Cauca

		Cauca	Norte de Santander	Quindío	Risaralda	Valle del Cauca
Life expectancy at birth, in years (2015–2020)*	Women	76	77	78	79	81
	Men	69	69	72	72	72
Ischemic heart disease	Women	55	62	89	82	73
	Men	85	97	142	128	115
Hemorrhagic stroke	Women	18	15	18	19	23
	Men	18	15	18	19	23
Chronic disease mortality rate (2014) (per 100,000 inhabitants)*	Women	9	22	16	16	17
	Men	10	24	18	18	19
Diabetes mellitus	Women	9	20	17	19	20
	Men	8	18	15	18	18
Chronic obstructive pulmonary disease	Women	13	20	53	47	26
	Men	19	30	76	68	37
Total number of cancer-related deaths (2014)**		836	1058	680	1,080	4,198
Palliative care services rendered per 100,000 inhabitants (2016)*		0.36	0.22	1.23	0.21	0.58
Total population (2016)*		1,391,836	1,367,708	568,506	957,254	4,660,741

SOURCE: Prepared by the authors based on data from the Colombian Observatory for Palliative Care* and the National Cancer Information System**

Palliative Care in Latin America, in 2013 Colombia's level of palliative care development was classified as 3a, meaning that palliative care is patchy in scope. As we will see in the next section, despite the country's recent advances—namely, the development of a regulatory and policy framework that recognizes palliative care as necessary for guaranteeing the right to health—numerous difficulties continue to impede patients' ability to access such care when they are at the end of life, particularly in non-major cities of the country (Pastrana et al. 2013).

Demographic, epidemiological, and social changes in the Colombian population reveal the clear need for an expansion and deepening of palliative care at all levels. In 2016, there were 4.4 palliative care facilities per 100,000 residents.⁸⁵ This figure unveils the near impossibility of such care for many people in the country (Observatorio Colombiano de Cuidados Paliativos 2016, 112). As demonstrated in the table below, of the departments we studied, only Quindío has at least one palliative care facility per 100,000 residents.

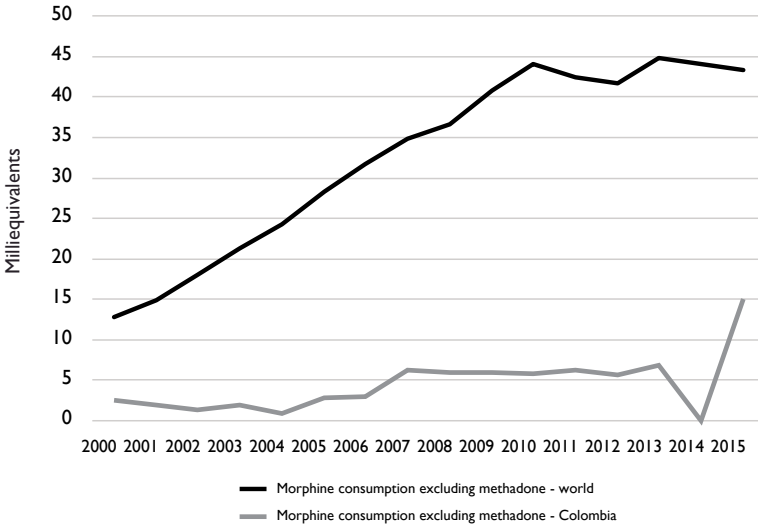
Opioid medicines play an essential role in palliative care, considering that pain relief is one of the top five priorities of patients who are at the end of life (Singer, Martin, and Kelner 1999). However, despite the gradual expansion of palliative care in the country, opioid consumption remains low, which suggests that patients' pain is being managed only partially. In 2015, Colombia's consumption of morphine milliequivalents⁸⁶ (excluding methadone) was 15.18 mg per capita, compared to the global average of 43.48 mg per capita. When analyzing palliative care in a given country, it is necessary to look both at the total consumption of morphine milliequivalents and at the consumption of morphine milliequivalents excluding methadone, since a significant portion of methadone consumption in a country where heroin is used is likely due to maintenance treatment, not

85 These figures are departmental totals; municipal-level data is not available. We can safely assume that a large portion of these services are located in departmental capitals, which are where specialized health care facilities tend to be concentrated.

86 The morphine equivalence metric was developed by the Pain and Policy Studies Group based on information from the World Health Organization and the International Narcotics Control Board. The metric allows for equivalent comparisons across countries with regard to their consumption of the main opioids used to treat pain, namely fentanyl, hydromorphone, morphine, methadone, oxycodone, and pethidine. See Pain and Policy Studies Group (n.d.).

pain relief. As seen in figure 5, morphine consumption has increased in Colombia, particularly during the latter half of the 2000s.

Figure 5
Morphine consumption excluding methadone (milliequivalents) in Colombia and the world



SOURCE: Pain and Policy Studies Group

NOTE: According to the National Narcotics Fund, data for 2014 were reported by the national government but were not included in the International Narcotics Control Board’s report

One key barrier to the provision of palliative care in Colombia is the lack of training among health practitioners. As discussed earlier, modern medicine—worldwide and in Colombia—is focused on curative approaches, meaning that treatments such as palliative care are not emphasized in primary care training. Health professionals, when faced with the reality of a patient’s death, often lack the training and tools needed to offer solutions to their patient. This lack of palliative care education has a direct impact on opioid prescription: given that opioids are controlled substances, that they have important side effects, and that they require the prescribing physician to have specific knowledge on the topic, physicians are often reluctant to prescribe them, even when a patient’s pain warrants it.

According to the Colombian Observatory for Palliative Care, in 2016 there were six medical schools in Colombia that included palliative care in their curricula, three that offered it as an elective, seven programs for

palliative care continuing education, and three post-graduate degrees in palliative care⁸⁷ (Observatorio Colombiano de Cuidados Paliativos 2016, 17). Such training is concentrated in Bogotá, Medellín, Cali, and Bucaramanga, meaning that most of the country's professionals in medicine, nursing, and psychology graduate without receiving any education in this area and that the vast majority of cities lack practitioners with palliative care expertise. In light of the limited options for obtaining a specialty in palliative care in Colombia, some practitioners go abroad for postgraduate studies; however, upon their return, they have trouble validating their degrees, which not only limits their career opportunities but also makes it difficult for the IPSs that employ them to meet the requirements for becoming accredited palliative care providers.

Is Palliative Care Effective?

Modern medicine has altered the courses of life and death. In the past, death could come at any moment and was a quick process. Today, thanks to medical advances, human beings live much longer and can go through cycles of ill health and recovery, or a slow and prolonged decline. Modern medicine has converted death into a process that is dragged out and put off. Paradoxically, this period in which the body and mind deteriorate is largely overlooked in medical practice, which is focused on “fixing” things and on medicalizing death, relegating to a back seat that which has no solution. As Gawande observes, advances in modern medicine have unleashed two revolutions: a biological transformation of the life course and a cultural transformation of how we perceive and embark on that life course (Gawande 2014, 28–29).

Our social and cultural reticence to speak honestly about death has consequences for the quality of life during our final moments. Without a clear path for dying, the process is left to the imperatives of technology—of machines that give us a few days more—without a clear idea of what truly matters (*ibid.*, 9). Palliative care allows us to talk about the unsolvable and to see the possibilities that the moment offers; it realigns the therapeutic approach toward an approach whose priority is to manage symptoms, relieve pain, and provide comfort for patients and their loved ones. Health professionals who are present during this time are well aware

87 These degrees are offered in medical, psychology, nursing, and social work schools.

that empathetic listening and respect are therapies in and of themselves (Kleinman 1989, 154).

Medicine's aversion to addressing end-of-life processes is especially evident in care for the elderly. In 2001, a group of researchers in the United States monitored the evolution of 568 men and women over the age of seventy who were at risk of disability due to chronic health problems, a recent illness, or cognitive decline. Half of these individuals were cared for by general practitioners, and the other half were cared for by a team of geriatric professionals. After eighteen months, even though the proportion of deaths was the same in both groups, those who had been under the care of geriatricians were 25% less likely to develop a physical disability, 50% less likely to become depressed, and 40% less likely to require home care (Gawande 2014, 44).

Gawande draws on his personal transformation as a physician who used to avoid talking about death with his patients, and who used to instruct his medical team to refrain from honestly discussing patients' status, to shed light on the true potential and impact of curative approaches. He notes that he and his colleagues would effortlessly discuss the risks of surgery and other drastic procedures—chemotherapy, radiation therapy—yet they could not bring themselves to discuss whether these treatments would actually give their patients the lives they had previously known. In today's medicine, the end of life has become plagued with uncertainties: When should we accept that we have lost the battle? What can we expect to occur? What can medicine do to relieve the physical and emotional pain caused by a patient's illness? Palliative care offers an answer to these questions, which physicians have largely ignored or are unable to address due to a lack of training.

A 2010 study found that patients who received palliative care not only experienced less suffering at the end of life but also lived 25% longer than those who did not receive such care. In this regard, Gawande notes that modern medicine has failed so spectacularly in its decision-making approach that doctors end up inflicting harm on their patients rather than addressing our destiny as mortals. As he writes, "the lesson seems almost Zen: you live longer only when you stop trying to live longer" (Gawande 2014, 177–8).

In another study, a health insurance company in the United States offered its policyholders with a life expectancy of less than a year the option of receiving palliative care alongside their regular curative treatment; the

company then created a control group consisting of patients who received only curative care (ibid., 176). The two-year study revealed the powerful impact of palliative care: the first group of patients visited the emergency room half as much as the control group, and their use of hospitals and intensive care units decreased by two-thirds (ibid.).

International health and human rights bodies, recognizing the effectiveness of palliative care, have called attention to the need to include such care in countries' health systems. The World Health Organization, during its 67th session in 2014, adopted Resolution 67.19 entitled "Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course." This resolution recognizes the need to integrate palliative care services into comprehensive health services in such a way that improves patients' quality of life (Pereira-Arana 2016, 15). The Americas witnessed important progress in this area in 2015, with the approval of the Inter-American Convention on Protecting the Human Rights of Older Persons, which establishes specific state obligations regarding the integration of palliative care into health systems and into care for the elderly (ibid., 12).

Palliative care is thus an approach that should be safeguarded in any health system, as it improves the quality of life for patients and their families, is cost-effective, and respects human dignity. Although Colombian law recognizes palliative care in this way, the law's implementation leaves much to be desired.

Legal and Policy Response toward People in Need of Palliative Care

In terms of pain management, Colombia is a pioneer in the region: in the 1980s, the country's first pain management clinic, in Medellín, was opened, and foundations were created in Valle del Cauca and Bogotá (Pastrana et al. 2013, 52). However, these first steps were few and far between, were based in large cities, and lacked an accompanying regulatory framework for the development and application of palliative care at all levels, as well as adequately trained practitioners. In 1995, the government founded the National Cancer Institute, which provides specialized training in palliative care.

Palliative care thus emerged in Colombia as a privilege of the few, available in specialized clinics (usually hospices) and paid for out of

patients' pockets or through supplemental health insurance plans (Del Río and Palma 2007, 18). This was the general panorama between the 1980s and the early 2000s. The country's national cancer policies touched on pain management, but they did not adequately incorporate the concept of palliative care, thus neglecting the comprehensive approach that is required in this area of health.

Parallel to this, medical schools began offering continuing education in palliative care. The first such program in Colombia was established in 1998. By 2016, there were six such programs on palliative care, and one on pain medicine (Observatorio Colombiano de Cuidados Paliativos 2016, 112). This improved training—both in Colombia and as a result of Colombians who studied abroad and came back to practice medicine—strengthened the profession in such a way that it has become a key actor in public policy settings. In 1996, the Colombian Association for Palliative Care⁸⁸ was established to bring together doctors specializing in palliative care, and in 2014 the similarly named Palliative Care Association of Colombia⁸⁹ was formed to bring together a broader range of professionals with experience in palliative care. In addition, in 2016, the University of El Bosque inaugurated its Colombian Observatory for Palliative Care,⁹⁰ which compiles, updates, and publicly shares information on public policies, education, service provision, opioids, and health technologies as they relate to palliative care. Further, in 2015, the Colombian Network for Education in Palliative Care was formed; this network comprises professors from four Colombian universities who seek to strengthen palliative care training in medical schools, nursing schools, and psychology schools (see Red Colombiana de Educación en Cuidados Paliativos 2015).

All of this demonstrates that professional associations, the hospice movement, and academia have sought to strengthen palliative care in Colombia, even prior to this field's incorporation into national health policies. In particular, this network of interested parties has advocated for reforms aimed at making opioids more available, particularly by extending the number of days that a single opioid prescription can cover and requiring each department of Colombia to have at least one accredited pharmacy for round-the-clock opioid dispensing (see Universidad de La

88 See <https://www.accpaliativos.com>

89 See <http://paliativoscolombia.org>

90 See <http://occp.com.co>

Sabana 2019). Prior to 2009, opioid prescriptions could cover only a ten-day dose; thanks to advocacy efforts by these groups, the maximum period was later extended to thirty days, thereby easing access for patients and their families in cases where opioid therapy is needed for long periods of time. These reforms, together with improvements in palliative care education and the intensive dialogue between physicians and health authorities responsible for regulating controlled medicines, led Human Rights Watch, in 2011, to name Colombia as a site of best practices in improving pain management in the Americas (Human Rights Watch 2011, 46).

Nonetheless, palliative care was being provided absent a regulatory framework, which meant that it was not covered by the country's Health Benefits Plan and thus had to be paid for out of pocket or through supplemental insurance, putting it out of reach for the vast majority of those in need. In fact, existing regulations lent themselves to conflicting interpretations, for the Ministry of Health's Resolution 5261 of 1994—which regulates access to health services in Colombia—can be read as simultaneously including and excluding palliative care from the country's package of health services. Article 18 of the resolution, which regulates exclusions, states that all procedures and interventions “that are not targeted at the *diagnosis, treatment, [or] rehabilitation* of an illness” shall be excluded, thus precluding coverage of non-curative treatments; however, this same provision, in subparagraph (i), notes that in cases of chronic, degenerative, or terminal illnesses, “palliative therapy for pain *may be provided*” (emphasis added). This provision, as highlighted by the author of a 2010 congressional bill on the issue, placed a responsibility, “though a *vague and inconclusive* one, on EAPBs toward the terminally ill population, with respect to palliative care.”⁹¹

This regulatory vacuum, open to the interpretation of EAPBs, led to the routine denial of coverage for palliative care. It is impossible to know how many patients were denied this care, but some of them filed *tutelas* (writs of constitutional protection) that eventually made their way to the Constitutional Court, paving the way for judicial recognition of palliative care as part of the rights to health and to life.

91 Congreso de la República, *Informe de ponencia para primer debate al proyecto de ley número 290 de 2011 Cámara - 138 de 2010 Senado*, 2011 (emphasis added).

In 2003, in Sentence T-560,⁹² the Constitutional Court handed down its first ruling on the issue of palliative care. The claimant—the son of a patient with terminal cancer—had requested palliative care from his mother’s EAPB, Cajanal, as such care had been prescribed by the National Cancer Institute; nevertheless, the EAPB refused to provide the treatment, arguing that it was not included in the country’s basic health plan. The court of first instance rejected the lawsuit, noting that the claimant had not demonstrated his inability to pay out of pocket for the costs of the treatment, a requirement set by the Constitutional Court in health-related cases such as this one. By the time of that first instance ruling, the patient had passed away, but the Constitutional Court considered it necessary to rule on the substance of the case. In its judgment, the Constitutional Court upheld the first court’s ruling solely on the basis of the patient’s death, but it ordered that copies of T-560 be sent to the Office of the Attorney General and the Office of the Inspector General so they could determine whether follow-up enforcement actions were necessary. Although Sentence T-560 does not advance formal recognition of palliative care as part of the right to health, it calls attention to the following:

In a social state subject to the rule of law (article 1 of the Constitution), founded on respect for human dignity and preservation of the value of life, it is unacceptable that economic interests be used to deny a person under such conditions *the opportunity to preserve their existence in a dignified manner—that is, without pain, without anguish* . . . Patients in such situations should not be left to die but rather *have a right to certain minimum conditions for pain relief* and for the hope of recovery and a prolonged life, should they so desire. Therefore, as the Court has instructed, the state must offer terminally ill patients who are experiencing intense suffering all of the possibilities for continued life, making it the state’s obligation to provide palliative treatment for pain.⁹³

In 2006, the court received a case in which the husband of a patient with terminal cancer requested that the Cruz Blanca EAPB hospitalize his wife, as it had not been possible to manage her pain at home and they were unable to afford a nurse. Although the patient had been enrolled in the Hospital at Home program, she received home visits only every

92 Corte Constitucional Court, Sentencia T-560 de 2003, July 11, 2003.

93 *Ibid.* (emphasis added).

seventy-two hours, which was insufficient for her needs and was an inadequate solution for her spouse, as he had to continue working and could not provide the care himself. The court of first instance ruled in favor of the claimant and ordered the National Cancer Institute—an entity with which the IPS did not have an affiliation agreement—to provide a medical opinion and an evaluation of the patient’s needs. The court of second instance revoked the ruling following an appeal by the EAPB.

The second instance court held that the judge of first instance had exceeded his authority in ordering a third party (the National Cancer Institute) to provide an opinion. In Sentence T-514 of 2006,⁹⁴ the Constitutional Court gave the EAPB forty-eight hours to provide permanent medical care for the patient, following a detailed assessment of the patient’s palliative care needs and keeping in mind her husband’s financial limitations. The court thus overruled the holding of the second instance court. In this case, it is worth noting that the EAPB defended its actions, claiming that it had complied with all of the physician’s orders—for example, home hospitalization—but that these programs, because they were not palliative care programs as such, lacked the capacity to offer the solutions required by the family.

In another judgment, Sentence T-1087 of 2007, the Constitutional Court reviewed a case in which palliative care had been denied to an elderly patient on the grounds that such care was excluded from the subsidized health regime.⁹⁵ The claimant—a seventy-one-year-old man—needed palliative care not just because of his illness but also because he had no family who could take care of him. The EAPB from the subsidized regime denied this request, arguing that palliative care was excluded from the obligatory health package for this regime, which provides such treatment only for cancer and for disastrous and life-threatening illnesses, neither of which the claimant had. Following this refusal, the patient then requested the care from the corresponding departmental and municipal health authorities, who also refused to provide it. These health authorities indicated that their denial did not violate the patient’s right to health and that such care should be provided by the family—an argument that clearly ignored the patient’s family situation. Further, the departmental health authority stressed that the provision of these services, which are

94 Corte Constitucional, Sentencia T-514 de 2006, July 6, 2006.

95 Corte Constitucional, Sentencia T-1087 de 2007, December 14, 2007.

first-level services, is the responsibility of the patient's EAPB, Salud Cónдор. The court of first instance ruled in favor of the claimant, holding that in light of his lack of family, the state must assume responsibility for his care; it ordered the municipal government of Pasto to enroll him in the programs necessary to ensure his access to such services. The municipal government appealed the ruling, which was subsequently overturned on various grounds, including the fact that the patient's palliative care had been prescribed by a nurse and not a physician.

In Sentence T-1087, the Constitutional Court affirmed the right to health as a fundamental right for the elderly, given that they are subjects of special constitutional protection, according to article 46 of the Constitution. The court also emphasized that accessibility is a key component of the fulfillment of this right and that it must abide by the principles of nondiscrimination, physical accessibility, and affordability. All of these needs for differentiated treatment were present in the case at hand, which centered on an elderly individual who lacked family and who belonged to the subsidized health care system. As a result, argued the court, services that fall outside the Health Benefits Plan but are necessary for fulfilling the right to health must be provided by regional health authorities; and when the individual who requires the services is a subject of special constitutional protection, the EAPB must fulfill this responsibility in order to protect the right more efficiently. The court also reiterated that according to Resolution 5261 of 1994, palliative care "may" be provided and should not be interpreted as being automatically excluded from the Health Benefits Plan. Lastly, the court ordered Salud Cónдор to refer the patient for a medical evaluation to determine what care was needed and to provide those services, regardless of their inclusion in the Health Benefits Plan, in light of the patient's manifestly vulnerable situation.

The country's legal vacuum, together with the limited availability of palliative care in the country, was thus contributing to the profound neglect of patients in need of such care. In 2010, Congress began debating the first bill to provide a normative framework for palliative care in Colombia. As noted by Congreso Visible, it took four years—and two instances of judicial review by the Constitutional Court, due to objections from various legislators—for this bill to pass both houses of Congress and finally become law (Congreso Visible n.d.).

In 2012, a first round of objections from legislators argued that the bill had constitutional and other legal shortcomings, which led the court

to return it to the House of Representatives for adjustments. Then, in a second round of objections, legislators argued that in light of articles 1, 4, and 5(4) of the bill⁹⁶—which, in their opinion, regulated the fundamental right to life and the human dignity of patients—the proposal should have been treated as a statutory law bill. They also objected to the fact that these articles did not provide for the family’s involvement in the decision whether to prolong the life of a patient with brain death. Lastly, they argued that the bill’s provisions on patients’ right to create an advance directive was regulating Sentence C-239 of 1997 of the Constitutional Court. In that judgment, the court had addressed the human rights tensions surrounding the issue of euthanasia, removing criminal penalties for the practice of mercy killings, establishing the right to die with dignity as a fundamental right, and calling on Congress to regulate the practice. These legislators were opposed to this practice and saw the bill’s treatment of advance directives as a form of regulation of euthanasia.

96 The articles in question read as follows (emphasis added):

Article 1. This law regulates the right of persons with terminal, chronic, degenerative, and irreversible illnesses to palliative care that seeks to improve the quality of life not only of these patients but also of their families, through the comprehensive treatment of pain and alleviation of suffering and other symptoms, keeping in mind their psychopathological, physical, emotional, social, and spiritual aspects, in accordance with the clinical practice guidelines established by the Ministry of Health for each pathology. Furthermore, it confirms *the right of these patients to voluntarily, and with advance notice, withdraw from unnecessary medical treatments that do not adhere to the principle of therapeutic proportionality and do not represent a dignified life for the patient*, specifically in cases where a terminal, chronic, degenerative, and irreversible illness has been diagnosed that has a substantial effect on the patient’s quality of life.

Article 4. So long as there exists a chance of alleviating or curing a patient’s illness, physicians shall use the methods and medicines at their disposal or reach. *When a patient’s brain death has been diagnosed, the physician is not obligated to maintain the functioning of other organs through artificial means*, provided that the patient is not a candidate for organ donation.

Article 5(4). The right to sign an Advance Directive: *Any person, healthy or in a state of illness, with sound mind and legal powers, with full knowledge of the implications of this right, may sign an Advance Directive.* Such a document shall indicate the person’s decision, in the case of a terminal, chronic, degenerative, and irreversible illness with a substantial effect on his or her quality of life, to not undergo unnecessary medical treatments that do not extend a life of dignity, and, in the case of death, the patient’s willingness or not to donate organs.

In Sentence C-233 of 2014, the court upheld the law’s enforceability, determining that legislators’ claim that the bill should be processed as a statutory law was unfounded. With regard to their objections over article 1 (concerning the right of patients with terminal, chronic, degenerative, or irreversible illnesses to cease unnecessary treatments that are considered disproportionate and futile) and article 5(4) (concerning the right to sign an advance directive), the court held that an advance directive does not constitute an instrument of euthanasia and is actually in accordance with medical ethics and the need to avoid therapeutic cruelty. Moreover, the court clarified that this right facilitates application of the principle of proportionality, for it prevents patients with irreversible illnesses from being subjected to curative treatments that have no possibility of curing; as a result, an advance directive does not interfere with the right to life, since it does not involve a decision to prematurely end one’s life. As the court concluded:

[A patient’s advance directive] does not involve the decision whether or not to remain ill, nor, indirectly, whether or not to continue living; as a result, *the signing of an advance directive does not have any effect on the core content of a patient’s right to life—or their right to health.* In the same vein, an advance directive is not inducing death or bringing human existence to an end and, accordingly, is not authorizing any procedure related to euthanasia.⁹⁷

With regard to legislators’ objections over article 4, which frees physicians from the requirement to keep a brain-dead patient on life support, the court held that this provision was not regulating any aspect of any fundamental right, as legislators had claimed, nor was it empowering to physicians to decide on terminally ill patients’ end of life, for “it does not determine anything about the patient’s life, nor any aspect related to when a patient dies, since the patient is already in a state of brain death.”⁹⁸ The court therefore concluded that these provisions need not be classified as statutory ones.

In 2014, Congress finally approved Law 1733 “regulating palliative care services for the comprehensive treatment of patients suffering from

97 Corte Constitucional, Sentencia C-233 de 2014, April 9, 2014, p. 72 (emphasis added).

98 Ibid., p. 71.

terminal, chronic, degenerative, and irreversible diseases at any phase of illness” (hereafter the Palliative Care Law). This law includes provisions on the rights of terminally ill patients and those with high-impact chronic illnesses, including the right to palliative care and the right to information (art. 5). It also obligates EAPBs to “guarantee palliative care services to members with terminal, chronic, degenerative, irreversible, and high-impact illnesses, with a particular emphasis on [ensuring] coverage, equity, accessibility, and quality within their service networks at all levels of care, in accordance with medical relevance and the content of the Obligatory Health Plan” (art. 6).

With regard to opioid medicines, the Palliative Care Law makes explicit reference to the duty of the Ministry of Health, the National Narcotics Fund, and EAPBs to guarantee round-the-clock access to and availability of these medicines (art. 8). Following the law’s passage, the Ministry of Health issued Circular 022 entitled *Guidelines and Directives for Managing Access to Opioid Medicines for Pain Relief*, reiterating service providers’ and Regional Narcotics Funds’ obligation to ensure that these medicines are in supply and available 24/7. However, as we will see below, this is not the reality in many parts of the country.

Given the law’s fairly recent passage, palliative care coverage remains far from universal. As we will see later, this is due to several factors: a lack of palliative care training in medical schools, persistent opiophobia, and structural failings of the health system.

That said, social and regulatory changes have led to an expansion in the provision of palliative care services: between 2011 and 2016, the existence of such services grew by 500%, from 49 accredited facilities to 243. However, this growth has been concentrated in the center of the country (namely, Bogotá, Antioquia, Valle del Cauca, and Atlántico), with the rest of Colombia still lacking accredited IPSs (Observatorio Colombiano de Cuidados Paliativos 2016, 112). In addition, as we discovered in our fieldwork, several of the IPSs that are listed in the Special Registry of Health Service Providers as accredited providers for “pain and palliative care” actually do not provide any kind of palliative care. This suggests that the increase in the total number of service providers does not necessarily mean a broadening of palliative care in some cities.

In the wake of the law’s passage, only two cases related to palliative care—and only tangentially so—have reached the Constitutional Court. The first case concerns a minor whose parents sought protection of his right to die with dignity, as he was suffering from a number of problems

linked to his cerebral palsy; in particular, his parents noted, he suffered from a constant lack of oxygen, and the EAPB was failing to provide the necessary oxygen tanks. The parents' request for euthanasia had been forwarded to their son's EAPB but was ignored. The Constitutional Court ruled on the case via Sentence T-544 of 2017. Although the case centers on euthanasia, the court's judgment mentions the provision of palliative care during the final phase of the minor's life—during which time the EAPB remained silent on the parents' request for euthanasia—and notes that such care provided relief for the family and the patient. The court's ruling quotes the boy's mother:

The doctors said that my son needed palliative care, in order to sedate him and prevent pain and anxiety while trying to breathe. Even though Francisco's⁹⁹ medical records say that he died from seizures, the truth is that he died from the very palliative care,¹⁰⁰ which allowed him to have a dignified death, which is why I had been requesting for a long time, since the majority of his doctors said that he would eventually suffocate.¹⁰¹

The other ruling, Sentence T-423 of 2017, centered on a similar case, in which a young patient had requested and been denied euthanasia, after which point her mother filed a lawsuit against the EAPB. In both of these cases, palliative care was provided to the patients, but the court still ruled on the matter, reiterating that Colombian law protects the right to a dignified death and that the issue is already regulated by Ministry of Health Resolution 1216 of 2015.

Beyond these two cases, no other lawsuits have been filed in the wake of the Palliative Care Law to allege the denial of palliative care. But this does not mean that health entities are fully complying with the law, for as we will see in the next section, the availability of palliative care is extremely insufficient, and there is still a significant lack of knowledge in the area.

Access to Palliative Care

In theory, according to the Palliative Care Law (Law 1733 of 2014) and regulations for the Statutory Health Law (Law 1751 of 2015), patients can access palliative care and medications for pain relief as soon as they

99 The ruling changed people's names in order to protect the minor's privacy.

100 Palliative care was not the cause of the boy's death, even though the mother's testimony could be interpreted this way.

101 Corte Constitucional, Sentencia T-544 de 2017, August 25, 2017, p. 10.

so require and their doctor orders such treatment. However, patients' unfamiliarity with this option, the lack of affiliation agreements with IPSs that are accredited palliative care providers, the lack of trained personnel, and bureaucratic barriers that limit the availability of and access to opioid medicines are just some of the barriers that stand in the way of palliative care access for patients with terminal and chronic illnesses, among others, which ultimately affects the enjoyment of their right to health.

The remainder of this chapter describes the process for accessing palliative care services and medicines in each of the five cities, offers a diagnosis of the main barriers faced by patients when seeking this care, and outlines the impacts that both illness and the medical process has on patients' family and social lives.

To provide context for our analysis, we will first highlight two testimonies from the relatives of patients with chronic and terminal illnesses who have had to deal firsthand with the health system barriers that impede access to the care and medicines their loved ones need to relieve their pain.

Martha

My mom, María Rebeca Bejarano de Cuero, was sick for many years. She would barely eat and was very underweight. She said that she had a really sore throat. We sought medical help several times, but nobody took her seriously. One general practitioner said that my mom was anorexic and referred her to a psychologist, but they never ordered tests to see what was in her throat. When she couldn't take the pain anymore, we decided to pay out of pocket for an endoscopy. My mom had cancer, and it was already really far along. We requested treatment from the EAPB, and since there isn't any chemotherapy in Santander [de Quilichao], the paperwork to have her referred to another city took three months. Even though they prescribed medicine for her pain, they never delivered it; I had to buy illegal morphine for my mom. The pain was unbearable, even for me, who wasn't the one experiencing it.

Juan

My wife, María, was diagnosed with breast cancer three years ago. It took the EAPB a really long time to authorize her chemotherapy, and the cancer metastasized in her spine. I had to file a tutela to get them to provide her care, and after that they sent us to Cali. For three months, I slept on the hospital floor to be able to be there with her because we don't have

enough money to pay for somewhere for me to sleep. There, they told us that she could request palliative care, but the EAPB has refused to provide any of it.

Pathway to Access in Armenia

According to the Special Registry of Health Service Providers, there are currently seven IPSs accredited to provide palliative care, four of which are for cancer patients. We conducted in-depth interviews with three of these facilities: Sanus, Oncólogos de Occidente, and La Sagrada Familia Clinic. We also interviewed one IPS that is not accredited but is developing a palliative care program for future implementation: San Juan de Dios Hospital. Of the three accredited facilities that we interviewed, Sanus and Oncólogos de Occidente have functioning palliative care programs for cancer patients, and Sagrada Familia Clinic, a second-level IPS, provides care for acute pain crises and thus needs accreditation to administer opioids. This last facility is also considering rolling out a palliative care program in the future.

Generally speaking, the IPSs we interviewed in Armenia explained that the process for accessing their services begins with a referral from a physician, usually an oncologist, given that the majority of the patients who are referred there have cancer. Once a patient obtains this referral, they must go to their EAPB, which then indicates which IPS is part of its network. One of the IPSs we interviewed mentioned that the EAPBs look at the patient's stage of illness when referring them to palliative care; however, based on other data that we gathered in the field, we cannot conclude that this is standard procedure. Thus, patients may potentially receive this care only during the last six months of their life.

Once a patient is referred to the IPS, they will receive a variety of services depending on the care model used by the facility. The two IPSs with palliative care programs each have an interdisciplinary team that provides care for patients and which includes professionals who are trained in palliative care, psychology, psychiatry, physical therapy, and nursing. One of the IPSs also offers respiratory therapy and nutrition services. After the team evaluates the patient, it determines whether the patient needs outpatient treatment or home care. For outpatient treatment, the patient will have regular appointments at intervals determined by the palliative care specialist. For home care, the two palliative care IPSs reported that they perform home visits at least once a month.

Ideally, the IPSs that are accredited to provide palliative care should also be accredited to dispense opioid medicines. However, these are two separate accreditation processes, and securing one accreditation does not include the other. For example, just one of these two IPSs with palliative care programs is accredited to dispense opioids, meaning that patients must sometimes go to another facility authorized by the EAPB to fill their opioid prescriptions. When we cross-checked information from the Special Registry of Health Service Providers with the Quindío Regional Narcotics Fund's list of facilities authorized to dispense opioids (which we obtained via a *derecho de petición*), we found that of the seven IPSs accredited to provide palliative care, only three are accredited to dispense opioids, and one of these is the IPS that reported not having a palliative care program as such.

In terms of barriers that emerge along this pathway to access, the IPSs we interviewed stated that some of the main hurdles relate to their lack of resources and EAPBs' failure to pay (which affects the IPSs' ability to hire health personnel) and to the cumbersome accreditation process for being able to dispense opioids. Although interviewees agreed on the importance of maintaining rigorous accreditation standards in order to ensure that services are of good quality and well functioning, they found the processes to be slow and the requirements excessive, which ultimately affects the accessibility of palliative care. Finally, interviewees highlighted the issue of access in rural areas: 20% of their patients live outside the city of Armenia, meaning that they face additional barriers related to distance and transportation.

According to the patients we interviewed, palliative care treatments are often erratic due to frequent changes in affiliation agreements between EAPBs and IPSs. One patient said that she was considering switching EAPBs but feared that she would be left without medical care and medicines during the transfer authorization process. Another barrier reported by patients is the delay in securing appointments with palliative care specialists, who tend to have booked calendars due to the dearth of professionals. These delays, in turn, often mean that patients' referrals expire before they get an appointment, which requires them to start the entire process over again.

With regard to the availability of and access to opioid medicines, the IPS staff we interviewed reported that the main obstacle is physicians' fear of prescribing and administering these medicines due to their lack of

training. As a result, access to these medicines is limited largely to the IPSs that provide more complex levels of care.

An additional barrier identified by health professionals in Armenia relates to the supply of official prescription pads for these medicines. One of the palliative care specialists at the non-accredited IPS that is currently developing a palliative care program noted that even though his facility is a third-level IPS, it has just three such prescription pads, which is vastly insufficient in light of the facility's large patient population. Another physician commented that once the official prescription pads run out, doctors can no longer prescribe these medicines. He also noted that when his facility requests a larger-than-usual quantity of controlled medicines, the Regional Narcotics Fund asks for additional documentation to justify the increase, which delays the dispensation of medicines to patients.

Meanwhile, patients identified multiple problems in accessing these medicines. One key barrier relates to the prescriptions themselves, which are valid for only fifteen days. In many cases, the medicine in question is out of stock for long periods at accredited pharmacies, meaning that patients' prescriptions expire and patients must schedule a new doctor's appointment in order to get another prescription.

Patients reported one good practice by one of the accredited pharmacies: when patients visit the pharmacy only to discover that the medicine is out of stock, the pharmacy later delivers the medicine to their home. Another interviewee, who lives in Quimbaya, commented that the pharmacies in her municipality are not accredited to dispense these medicines, so she must travel to Armenia to fill her prescriptions. Other patients told us that they have even had to file *tutelas* to be able to get their medicines, after multiple visits to pharmacies proved fruitless.

Our analysis of access to palliative care in Armenia, particularly access to opioid medicines for pain relief, revealed several barriers stemming from two of the most important actors in the health system: EAPBs and IPSs. We found that EAPBs lack sufficient numbers of affiliated IPSs to guarantee the delivery of specialized care to patients and that their non-compliance with their contracts with IPSs forces patients to rotate through multiple facilities to get the treatment they need. In addition, denials of care and medicines remain a problem despite the changes brought by the Statutory Health Law. This, together with the lack of trained personnel, leads IPSs to face serious financial problems as a result of their relationship with the EAPBs.

Finally, with regard to barriers to accessing opioids, we found that the number of accredited pharmacies is limited and that these establishments do not always have an adequate supply, causing patients to endure long periods without access to the medicines they need. The fact that just three of the IPSs accredited to provide palliative care are also able to dispense opioids vastly restricts patients' ability to receive comprehensive care, especially when they are facing the end of life at home without access to medicines to alleviate their pain.

Pathway to Access in Pereira

According to the Special Registry of Health Service Providers, there are currently ten IPSs accredited to provide palliative care in Pereira. During our fieldwork, we interviewed two of them. However, only one has a functioning palliative care program; the other closed its palliative care program because it lacked the financial capacity to fulfill the accreditation requirements. In any event, this facility offers care to patients experiencing pain due to chronic illnesses and cancer.

According to interviewees from the IPS with a functioning palliative care program, the process for accessing such care begins with a referral from the patient's EAPB. Once the IPS performs a medical evaluation of the patient, it determines whether the patient requires outpatient treatment or home care. The IPS assigns home care only to patients who live less than an hour away, as this allows the facility to respond quickly to patients' phone calls and to care for more patients since health workers do not have to travel long distances. The IPS also has a hotline that patients can call at any time.

This IPS uses the New Palex¹⁰² care model and works only with EAPBs that share the same approach, in which there is no predetermined limit to the number of visits that patients may receive. Despite this flexibility, health professionals acknowledge that in practice, home visits are conducted just once a month, which hinders their ability to monitor patients' progress. With regard to opioid dispensing, interviewees noted that the IPS would ideally like to be able to prescribe and administer these medicines during the patient's visit to the facility, but to be able to achieve this, it must first secure accreditation—a process that it was currently looking

102 Designed by the New Health Foundation, the New Palex method is a palliative care model in which providers can earn certification. See <http://www.newhealthfoundation.org/en/metodo-newpalex>.

into with the National Narcotics Fund and Regional Narcotics Fund—or have an ambulance, which is how programs with similar models operate in other cities.

The IPS's palliative care team consists of a chief nurse, an administrative assistant, a physical therapist, a social worker, two doctors, and a psychologist—all of whom are trained in palliative care—as well as a spiritual guide for those patients who wish to have such support. It also has a group of volunteers who raise awareness in the community about the importance of palliative care and who fundraise on behalf of low-income patients. With regard to opioids, since the IPS was not yet accredited to dispense them, its patients had to go elsewhere to fill their prescriptions.

As mentioned earlier, one of the IPSs we interviewed found the palliative care accreditation process to be excessive for small- and medium-scale IPSs wishing to offer such care. It also noted that health professionals are generally unaware of and uninterested in palliative care training, which makes it even harder for IPSs to meet the requirements. Further, one of the requirements is that an IPS's health professionals have obtained their palliative care specialty in Colombia, which imposes a critical barrier given the dearth of medical schools in Colombia that offer training on the issue and the limited availability of these programs.

With regard to care models, interviewees noted that despite the potential of home care programs in some facilities, the numbers of patient visits are limited due to the terms outlined in the package of services that the IPSs must negotiate with the EAPBs, which sometimes even determine which medicines physicians are allowed to prescribe. Further, they explained that the inability to administer medicines during home visits, together with accredited pharmacies' delays in providing these medicines to patients, means that patients often have no other choice than to make repeated visits to the emergency room. Like their counterparts in other cities, the IPSs in Pereira noted that patients have a hard time accessing certain medicines that are not included in the Health Benefits Plan. Finally, the IPSs are concerned that EAPBs are granting patients access to palliative care only during their last six months of life, in violation of international guidelines stating that treatment should be offered from the moment of diagnosis.

One woman we interviewed—the wife of a patient who died of cancer several months prior to our fieldwork—said that the main obstacle faced by her husband when seeking palliative care was the EAPB, which

did not readily authorize his prescriptions or his appointments with specialists. With respect to medicines for pain relief, she commented that the EAPB never authorized the dispensing of buprenorphine patches, which require changing every forty-eight hours, forcing the family to pay out of pocket despite their limited resources. Lastly, the IPS that was providing care to her husband terminated its contract with the EAPB due to nonpayment, halting her husband’s care and forcing him to die at home without the assistance he required—and under extreme pain. As she explained, “He was going to die eventually, but if there had been a little bit of support from the EAPB, everything would’ve been easier.”

Although Pereira has more accredited palliative care facilities than Armenia, the information we gathered suggests that there are nonetheless many barriers to accessing palliative care services and medicines that stem from structural failings in the health system, particularly with regard to EAPBs’ conduct and the country’s excessive regulations that prevent this treatment from being provided in facilities at lower levels of care. In terms of opioid availability, Pereira resembles the other cities mentioned above, where barriers relate to EAPBs’ refusal to authorize certain medicines, especially patches, which are not included in the Health Benefits Plan; the inability of prescribing physicians to actually dispense medicines due to the separate accreditation processes for service provision and opioid dispensation; and health authorities’ inflexibility toward new care models that seek to streamline these processes for patients.

Pathway to Access in Cali

According to the Special Registry of Health Service Providers, as of October 11, 2018, there were thirty IPSs in Cali accredited to provide palliative care. We interviewed six of them, all of which are also accredited to dispense opioids, according to information from Cauca’s Regional Narcotics Fund.

The pathway for accessing palliative care in Cali is similar to that in Armenia: the treating physician refers the patient to a palliative care program, and professionals from that program then evaluate the patient to determine which services will be provided, based on the patient’s needs and stage of illness. Some interviewees mentioned that emergency room doctors can also refer patients to palliative care programs.

As revealed by our qualitative data analysis, Cali has more advanced palliative care services than the other cities we studied. Some of the city’s

palliative care programs have been operating for more than ten years and have large teams of interdisciplinary professionals that include physicians, nurses, psychologists, social workers, and spiritual guides, all of whom are trained in palliative care.

In addition, these facilities offer structured programs for both cancer patients and noncancer patients, whether through hospitalization, outpatient treatment, or home care. With regard to hospital-based programs, one program director noted that patients who are hospitalized and require palliative care at the end of life are identified as “code lilac” and are placed in a private room that family members can visit regularly and where the patient receives psychosocial support. Another IPS even has a special care unit located outside the city that allows patients to go through their end-of-life process in a space that is more comfortable and welcoming than a hospital setting.

In terms of the home care programs, some IPSs specialize in this mode of care and conduct daily visits to their patients. During our fieldwork, we had the opportunity to accompany health workers on one of these trips and found that this kind of program facilitates communication among patients, family members, and health professionals because it allows health professionals to focus on patients’ unique needs and to ensure that their home environments cater to those needs.

As mentioned in this book’s introduction, collecting information from the EAPBs was very difficult. However, in Cali we had the opportunity to interview an EAPB that has a structured palliative care program. The person who oversees the program’s implementation told us that patients in need of palliative care are identified through searches in the EAPB’s database and through referrals from affiliated IPSs. To be included in this program, the patient must have either stage IV cancer, kidney disease, HIV, chronic obstructive pulmonary disease, cardiovascular disease, or respiratory disease, among others. Once the patient is identified, they are referred to an affiliated IPS that provides care based on the New Palex model. As highlighted by the EAPB, this program has resulted in 65% of deaths occurring at home, which provides better care for patients and reduces costs for the EAPB.

Although the provision of palliative care in Cali is good on the whole, some barriers to securing comprehensive care still exist. These hurdles relate to the subsidized health regime, the relationships between EAPBs and IPSs, and access to opioid medicines.

The IPSs we interviewed reported that access to palliative care is limited for patients who live in rural areas and that patients who belong to the subsidized regime have more difficulties accessing such care because IPSs have had to terminate their contracts with EAPBs in light of nonpayment. Further, very few EAPBs establish service packages with IPSs, instead paying for treatments on a case-by-case basis, which limits patients' ability to receive comprehensive care. In addition, the IPSs we spoke with noted that the EAPBs require that patients be in their last six months of life in order to access palliative care and that any type of treatment prior to this stage be provided as inpatient care. These accounts reinforce our findings in Armenia, where access to palliative care depends on the patient's stage of illness. With regard to the teams of professionals, one of the physicians we interviewed said that many programs "focus on physical pain but lack a comprehensive approach, such as through activities like family companionship. It has become a monopoly run by specialists."

Concerning access to opioids, unlike in Armenia, all of the IPSs we interviewed in Cali are authorized to dispense controlled medicines. However, in most cases, this authorization applies only to inpatient care and not outpatient or home care. One of the IPSs commented that it prescribes medicines for long periods of time—for example, one month—but the challenge is ensuring that patients effectively receive their medications once discharged from the hospital. According to one health professional, "The fact that the medicines are controlled is a barrier in and of itself," as it creates a lot of red tape: for example, the forms must be filled out by hand, there can be no crossed-out words, each medication must be applied for separately, and prescriptions may not be issued for several months' worth of medicine.

Health professionals also reported that despite improvements in the supply of opioid medicines, there are still short periods in which certain medications—such as methadone, hydromorphone, fentanyl patches, midazolam, and morphine drops—are out of stock. They attribute these shortages to the Regional Narcotics Fund's calculation of the city's opioid demand, which is based on previous consumption by accredited facilities and does not consider prescriptions written by physicians or by IPSs that are not accredited to dispense these medicines. This problem stems from the control mechanisms established by the International Narcotics Control Board and, in turn, from the National Narcotics Fund's lack of an estimated demand on which to calculate its opioid purchases. Nonetheless,

they noted that a quick fix has been made possible through direct purchase from the National Narcotics Fund. On another note, one interviewee referred to the substandard quality of the oxycodone being distributed, which does not effectively relieve patients' pain.

Meanwhile, the patients we interviewed agreed that there are many obstacles to accessing medicines, particularly due to the EAPBs. Just as in the case of Quindío, in Valle del Cauca there are not many accredited pharmacies, meaning that patients must travel to Cali to fill their prescriptions. Prescriptions have an expiration date, and when medicines are not dispensed in time, patients must re-request the prescription from their doctor. Patients also reported receiving just some of their prescribed medications and having to pay out of pocket for the others. EAPBs continue to deny coverage for medicines that are excluded from the Health Benefits Plan, even when such medicines can be dispensed through the MiPres program.¹⁰³

Cali has made significant improvements in its provision of palliative care services. The city has several accredited IPSs, interdisciplinary teams of professionals who are trained on the issue, civil society organizations that support patients through actions such as the provision of housing and meals for caregivers, and even an EAPB with a palliative care program based on international standards.

Given that Cali's IPSs and their teams of health professionals are intimately familiar with the provision of palliative care services, our fieldwork there allowed us to more concretely pinpoint administrative barriers impeding the prescribing and dispensing of opioids, such as the processes for filling out forms, the validity period of prescriptions, and the denials of medicines not included in the Health Benefits Plan, such as fentanyl and buprenorphine patches.

Pathway to Access in Santander de Quilichao

Unlike in the other cities, the palliative care situation in Santander de Quilichao is dire. The city lacks a single accredited palliative care provider, meaning that we did not interview any IPSs. According to information that we gathered elsewhere in the field, patients access specialized medical

103 Mipres is an online tool launched in 2016 by the Ministry of Health that allows physicians to prescribe any registered drug that they deem fit for their patients, even if the drug is excluded from the country's Health Benefits Plan.

services by first making an appointment with a general practitioner, who then refers them to a specialist or subspecialist. The problem is that these referrals are generally for services in other cities, such as Cali and Popayán, since there are not many specialists who reside in this municipality, and the few who do live there tend to have booked calendars.

The main health service provider in Santander de Quilichao is Francisco de Paula Santander Hospital, a second-level IPS that provides care not only for residents of Santander de Quilichao but also for those of another thirteen municipalities in the department of Cauca. Nonetheless, the facility has only seventy hospital beds. Although the hospital lacks a palliative care program, it occasionally provides emergency care to patients with terminal illnesses, who usually stay in the emergency room for one to two days to manage their symptoms and then, depending on their state, are discharged or moved to a hospital room. Opioids are dispensed only within the hospital, meaning that if a patient receives a prescription for these medicines, they must fill it at a pharmacy within the EAPB's network. Thus, patients in Santander de Quilichao who require specialized treatment or palliative care must travel to Cali to be able to access it, which requires significant time and resources. In many cases, patients and their caregivers do not have this luxury and must embark on the end-of-life journey without proper support or care.

In terms of the availability of opioid medicines, the hospital's pharmacy purchases medicines on a quarterly basis from the Regional Narcotics Fund, based on calculations of historic consumption. The purchasing process takes about a week, and in cases where the medicines are unavailable from the regional fund, the hospital purchases them directly from the National Narcotics Fund. According to our interviews with this hospital's health personnel, many patients have told these practitioners that the EAPB's affiliated pharmacy does not dispense opioids, forcing them to go back to the emergency room in order to become stabilized, thus creating a vicious circle. For morphine prescriptions, patients must travel to Cali or Popayán.

This situation is demonstrated by the case, mentioned earlier, of a woman patient who died from cancer without receiving any type of specialized care. The patient's daughter, Martha, who was her caregiver throughout the entire process, told us that her mother's illness was diagnosed extremely late and that there were many delays in obtaining authorization for the necessary exams. Due to these difficulties, they had to file a

tutela to get her mother the palliative care that her physician had ordered. Although they won the lawsuit, the EAPB never authorized the dispensing of her mother's prescription, and Martha was forced to purchase morphine illegally: "In Cali, I was able to buy morphine on the black market, even though it was really expensive."

Another patient with cancer told us that her EAPB had failed to provide timely treatment for her illness, which caused the cancer to metastasize to different organs. She then requested palliative care, which was denied. Finally, she filed a *tutela* that was rejected by the court on procedural grounds. As a result, she has had to travel to Cali for medical treatment, but her ability to access such care continuously is limited since neither she nor her caregiver has the economic resources to pay for room and board there.

Compared to the three other cities analyzed thus far, Santander de Quilichao has a seriously worrying situation in terms of palliative care services for patients who need them, as there are no accredited facilities and patients face barriers in filling their opioid prescriptions. Although Cali—a city with much greater service provision in this field—is relatively close to Santander de Quilichao, many patients are unable to travel there for treatment in light of their limited economic resources and the difficulties inherent in being ill. As a result, patients in Santander de Quilichao who suffer from terminal and chronic illnesses are extremely limited in their ability to access palliative care services, which restricts the enjoyment of their right to health.

Pathway to Access in Cúcuta

The case of Cúcuta has a similarly limited palliative care situation given that the city has just one IPS accredited to provide such care. However, unlike patients in Santander de Quilichao, patients in Cúcuta do not have a nearby city to which they can travel to access treatment.

In light of Cúcuta's lack of specialized services, we sought information from the IPSs that offer cancer treatment; we were able to interview four IPSs, two of which provide more complex levels of care. One of these IPSs is a new facility that has an oncology unit and attends to patients from both the contributory and subsidized health regimes. Although the IPS does not have a palliative care program, its personnel have identified barriers that their patients face in accessing cancer treatment. For example, in some cases the EAPBs refuse to authorize the dispensing of certain

medicines or the Regional Narcotics Fund is slow to deliver medicines to the facility's pharmacy, which inhibits the IPS's ability to offer comprehensive care for its patients. Health personnel try to ensure that their patients receive the medicines they need, but the challenge is when the patients are discharged from the facility and must fill their prescriptions in accredited pharmacies.

One of the workers we interviewed from another IPS noted that her facility does not refer patients to palliative care because health workers are not adequately informed about such services. In addition, the facility lacks an accredited pharmacy for dispensing opioids and is able to administer opioids only to patients who are hospitalized. There are also many problems concerning the dispensing of medicines to patients from rural areas. For example, sometimes the EAPB instructs patients to claim their prescriptions in the municipality in which they live, even if they are currently based in Cúcuta for treatment. The patients then go to their cities of residence to fill their prescriptions and find that the medicines are unavailable. Given the dearth of services in Cúcuta, people with the means to do so often seek care in other cities, such as Bucaramanga.

We also had the opportunity to interview one of the city's few palliative care specialists, who works at a third-level public hospital. She explained that her IPS is implementing an inpatient pain management program that administers whatever medicines are required by the patient. Once the patient is discharged, the program then prescribes the necessary medications. If the patient has trouble filling the prescription—whether due to a medicine being out of stock or because the EAPB refuses to authorize its dispensing—the doctor tries to find a suitable replacement; however, doing so requires that the doctor be trained in prescribing opioids, and such training opportunities are practically nonexistent in the department.

Moreover, medicine shortages—which can last between one and three months—mean that prescriptions constantly expire and must be renewed. Such administrative barriers interrupt patients' treatments, which has a negative effect on their health and well-being. With regard to home care, one IPS has begun to develop a telemedicine program with an EAPB. This is particularly important for patients who live in rural areas.

In Cúcuta, patients enjoy extremely limited access to palliative care in light of the dearth of accredited IPSs and specialized practitioners. It is concerning that even the IPS that provides care for cancer patients—who

are among those most urgently in need of palliative care—lacks general knowledge of the issue, unaware of where to refer its patients or how to provide comprehensive care that goes beyond a curative approach. Further, unlike Santander de Quilichao, Cúcuta lacks a nearby city to which patients can travel in search of alternatives.

Against this backdrop, the barriers in Cúcuta are even more severe than those in the other cities. Cúcuta's EAPBs do not have affiliated IPSs that provide such care, and they routinely refuse to authorize prescriptions. Further, when such prescriptions are approved, patients face administrative barriers such as medicine shortages in the EAPBs' affiliated pharmacies.

Barriers to Accessing Palliative Care

Having a terminal or chronic illness has serious impacts on a person's physical and mental well-being, as well as on the well-being of those around them—but a patient's inability to access palliative care and pain relief aggravates these impacts even further, leading to suffering that could have been avoided.

During our interviews with patients and their families, we inquired about their life stories and the ways their illnesses were affecting them. Most patients told us that they were experiencing depression due to their lack of pain relief, which was in turn affecting their family relationships because they often felt irritable, alone, and powerless. Depending on the stage of a patient's illness, they are sometimes able to maintain a certain level of independence. However, in order to successfully maneuver the health system's red tape and to access the necessary services and medicines, a patient needs the support of someone else—whether a relative or caregiver—who has the physical and mental stamina to deal with paperwork, delays, trips, and denials, as well as to care for the patient when symptoms get worse. In many cases, the *tutela* has been the only tool that has allowed patients to access the medical services they need—and for this, too, they need the support of someone who can take charge of filing the claim and staying on top of legal proceedings, given that many patients cannot afford a lawyer.

Several of the patients we interviewed are the primary breadwinners for their families. Their illness, coupled with their inability to access treatment or pain medication, directly affects their ability to continue working, which subsequently undermines the household economy. These patients

must use their already limited resources not only to cover regular family expenses but also to pay for services and medicines that their EAPBs fail to authorize, which sometimes require traveling to another city. Additionally, the denial of care that leads to unbearable pain for these patients means that they often end up in the emergency room, which wears the patients down even further, as well as the health system in general.

Barriers to accessing health services and medicines have devastating consequences not only for patients but also for the individuals—usually women—who care for them. When a person becomes ill, female members of the family, particularly those who are single and without children, are usually the ones who sacrifice their employment and educational opportunities to care for the patient. We witnessed this situation in Cali, where we met a seventeen-year-old woman who had put her life on hold in order to stay with her aunt at the Palliative Care Foundation. In the face of an inattentive health system, families decide that the responsibility for the patient's care will be the responsibility of whoever has the least possibility of contributing to the household economy, which, more often than not, is a woman. These women caregivers must therefore assume the task of managing their family member's illness while also coping with the suffering and pain alone and behind closed doors. Although progress has been made in documenting women's role in the care economy and how this contributes to the family income, scholars have yet to quantify the emotional, economic, and professional consequences that caring for a terminally or chronically ill family member has on a woman's life plans.

As a society, we have been taught that these situations are part of the private family sphere and that the health system and society in general should not bear responsibility for the burden generated by a person's terminal or chronic illness. Beyond the provision of services and medicines—which are already in themselves extremely limited—families also need a range of support during these situations, and it is this need that a palliative care approach seeks to fill. Actors in the health system should stop to take note of the concrete consequences that their processes and procedures are having on the lives of terminally ill patients and their families.

The barriers we found in the course of our research can be classified into three overarching groups: (i) lack of available health services; (ii) the control system for opioid medicines; and (iii) lack of training among health professionals in the areas of palliative care and opioid administration.

Lack of Available Health Services

Palliative care facilities, on the one hand, and pharmaceutical establishments, on the other, must each undergo their own procedure in order to become accredited facilities. For controlled medicines, this seems a reasonable standard considering the controls that are needed to manage the potential risks of such substances; but according to the health professionals we interviewed, both the accreditation process for palliative care facilities and the requirements for pharmaceutical services imply significant costs in terms of money and personnel. In our fieldwork, we encountered several IPSs that had accreditation to provide palliative care services but not to dispense opioids. This would not be an issue if patients could easily fill their prescriptions in nearby pharmaceutical establishments.

However, in practice, patients leave their palliative care consultations with a prescription in hand that, for any number of reasons, they are unable to fill, which translates into an unmet need for pain relief at the end of life.

In the opinion of many health practitioners, one crucial dilemma is the fact that palliative care enters the scene very late in the process. Their overall perception is that such care is reserved for the last moments of life and that the palliative care team is asked to intervene too late.

At the institutional level, although Colombia has a law incorporating palliative care—including opioids—into the Health Benefits Plan, the provision of such care outside the country's major cities is patchy due to financial issues in EAPB-IPS relationships. Interviewees continually referenced EAPBs' failure to pay IPSs, as well as the fact that municipalities outside departmental capitals often lack service providers. In practice, when the small handful of providers in a given city must cancel their contracts with a large EAPB, thousands of patients are left without access to palliative care. Likewise, EAPBs' refusal to authorize the dispensing of certain medicines, in violation of the Statutory Health Law, makes it difficult for patients to access the medications they need when they need them.

The vast majority of opioid medicines used in palliative care are included in the Health Benefits Plan, but a few (such as buprenorphine patches) are not—and these ones happen to be the most costly ones. Sometimes, when such medicines are prescribed, families pay out of pocket to obtain them, which adds to their already significant financial burden as a result of their loved one's illness.

Lastly, there is a structural issue concerning the accreditation of “pain and palliative care” facilities: for any given geographical area, a facility can appear in the Special Registry of Health Service Providers as an accredited palliative care provider, when the reality is that the facility only manages pain and does not offer palliative care as such. Considering that pain management and palliative care are two distinct interventions aimed at different groups of patients, it is important for health institutions to separate the accreditation into two categories.

Opioid Control Measures

Both the National Narcotics Fund and the country’s various Regional Narcotics Funds calculate their forthcoming opioid supplies by referring to consumption during the previous period; this means that estimated need is based on previously low consumption levels, which in turn are based on low prescription levels. As we have discussed throughout this book, a range of social, educational, institutional, and cultural barriers prevent physicians from prescribing opioids in a manner that allows patients to effectively manage their pain. This calculation method is not just a Colombian problem—as pointed out in 2015, the International Narcotics Control Board’s estimates system has been a failure across the globe, for it does not accurately reflect countries’ true medical need for opioids, resulting in “an endless cycle of underestimation” (Global Commission on Drug Policy 2015, 17). This is one of the main structural barriers standing in the way of access to opioid medicines, both for palliative care patients and for those who require methadone maintenance therapy.

With regard to the enforcement of regulations on opioid dispensing, we found barriers stemming from the design, interpretation, and implementation of these regulations.

In terms of regulations’ design, existing standards do not allow home care units to take opioids to a patient’s house; rather, caregivers must fill prescriptions under a separate process, which causes unnecessary delays and burdens. In addition, given that the accreditation of pharmacy services requires institutions to have significant human and financial resources, rural municipalities generally lack this kind of establishment. But the worst part is that when these rural residents travel to the nearest city big city to obtain their medicines, they encounter two barriers: high transportation costs and, in some cases, the pharmacy’s refusal to fill the prescription because of the paper on which it is written. Although regulations state

that opioids may be dispensed in a location other than the place they were prescribed, many pharmacies ignore this rule and refuse to provide the medicine. As a result, the patient or caregiver spends precious time and money only to end up with empty hands.

Difficult pharmacy experiences, according to the physicians we interviewed, are very common. Patients are turned away when the prescription has a crossed-out word, a minor error, or an unchecked box. In this way, rules are excessively applied without taking into account patients' extreme suffering and limited time left to live, which has severe repercussions for their quality of life. This kind of situation is common for patients who have been discharged from the hospital—with their pain symptoms under control—and who are given prescriptions to fill upon their release, but are unable to obtain the medicines due to a range of refusals from pharmacies. In some cases, this leads to pain crises that end up taking the patient to the emergency room, one of the last places a person wishes to be during the end of life.

Lack of Trained Professionals for Palliative Care and Opioid Treatment

One underlying factor related to the aforementioned structural barriers is the general lack of training on palliative care and pain management among health professionals.

As we described at the beginning of this chapter, Colombia has a critical educational deficit in this field, both at the level of medical school and at the level of continuing education. In terms of general medical care, this means that when patients who are in pain and need opioids arrive to a first- or second-level health facility, they will be treated by physicians who have not been trained in how to handle the end of life or how to prescribe opioids responsibly. Ultimately, they will leave the facility without a solution for their pain. In terms of specialized care, this deficiency means that most cities lack physicians who specialize in this area of medicine.

Finally, some of the health professionals we interviewed expressed their concern over physicians' unawareness of how to handle surplus medicines that are left in the hands of relatives and caregivers following a patient's death. Sometimes, family members deliver these medicines to the patient's treating physician. There is a lack of information on *puntos azules* (collection points for unused medicines), and many of these bins are not located in accessible areas, which means that surplus medicines—which

could be used by other patients or returned to the Regional Narcotics Fund, go astray.

Facing the end of life can have serious impacts on the mental and physical health of patients, their families, and their support networks. These impacts are aggravated by a lack of access to opioid medicines, which are critical for alleviating avoidable pain and allowing patients to have the frame of mind to make important decisions on their personal journeys. Palliative care is active holistic care aimed at improving the quality of life of patients with illnesses that cause severe suffering. It care includes access to opioid medicines, which are a key tool for pain relief and management (International Association for Hospice and Palliative Care 2019a).

Colombia has made significant progress in ensuring patients' access to palliative care, including through the passage of Law 1733 of 2014, which incorporates this care into the country's Health Benefits Plan and requires that access to opioids be provided twenty-four hours a day, seven days a week.

In practice, however, these legal provisions are far from reality. Fear of death is ubiquitous among patients, family members, and health professionals, making it easier to ignore the fact that the end is near and to abandon people who are in their final moments. Palliative care offers the possibility of providing support when a cure is no longer possible; but in addition to being enshrined in law, palliative care services must be accompanied by a social and cultural transformation in which we embrace death with as much ease as we welcome new life into the world.

In this complicated labyrinth in which we find ourselves, patients and their loved ones are at the mercy of the revolving doors of pain. Although there are solutions for physical symptoms—especially pain, which can be relieved with opioids—our obsession with “cures,” coupled with a generalized lack of knowledge and awareness, means that the end of life continues to be marked by pain. Making palliative care more available throughout the country offers the possibility of demystifying death and saying goodbye to the world calmly and painlessly.

Palliative care is a model that should be included in any health system in light of its ability to improve the quality of life of patients and their families, its respect for human dignity, and its cost-effectiveness. Colombia has taken important steps to ensure the provision of palliative care services, but these efforts have not been enough to guarantee access for

the vast majority of the population. As we will see in the following chapter, authorities at the local and national levels should implement effective measures that expand palliative care and medicines to other areas of the country beyond major cities.

CHAPTER 4

TOWARD HEALTH CARE FIT FOR PAIN RELIEF

If to be human is to be limited, then the role of caring professions and institutions—from surgeons to nursing homes—ought to be aiding people in their struggle with those limits. Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it the good we do can be breathtaking.

Atul Gawande, *Being Mortal*

An incurable illness, or the difficult journey of overcoming heroin dependence, challenges us to find solutions that allow people to enjoy a better quality of life and to alleviate their suffering with dignity. For the state and its health system, this poses both a challenge and an opportunity to discover and underscore possible solutions.

In this book, we have maintained that opioids, though not a magic bullet, are key for facilitating other important processes. In the case of palliative care, end-of-life pain management makes the battle more bearable for patients and their loved ones and lends the control needed by the patient to make decisions and to exit to the world. In the case of people who wish to overcome their heroin dependence, methadone helps ensure that withdrawal symptoms do not impede the individual from working on all of the other issues at play—rebuilding support networks, going back to school, resuming life plans. These medicines are essential because without them, none of these processes can take place. Their inclusion is thus indispensable as part of a comprehensive health care model.

True care for these communities of patients requires discarding the myth of the cure and learning to live with the impossible. Being rescued from death and redeeming oneself through abstinence are two myths that still permeate certain areas of care, preventing solutions from being offered to patients at the end of life and inhibiting methadone therapy from being seen as something other than “replacing one addiction with another.” In both spheres of care, practitioners who understand that a “cure” is not always possible base their actions on the principle of respect for the patient’s voice, making the person’s vital goals and autonomy the central focus.

In this book, we have documented how the repressive application of drug policies imposes barriers to accessing controlled medicines, which has a direct impact on human rights, particularly the right to health; we invite the development of other interpretations that place priority on the protection of human rights. Our research has also unveiled other obstacles that stem not from drug control measures but from issues related to health policies, physicians’ lack of training, and social and cultural attitudes around pain, death, and substance use disorders. Taken together, these barriers call attention to the fact that improved care for terminally ill patients and PWUD depends not only on making opioids more available and accessible but also on fostering political and cultural transformations that see these spheres of care as necessary elements of the full enjoyment of the right to health.

In this chapter, we present some final considerations, followed by public policy recommendations according to sector and sphere of care.¹⁰⁴ We end with a proposal for future research in the field of pain relief and the accompanying responsibilities of Colombia’s care systems.

Some Final Considerations

The lack of pain relief for patients facing the end of life and for PWUD underscores the fact that drug policies continue to focus on preventing the illegal diversion of controlled substances at the expense of ensuring these substances’ availability for medical purposes (Global Commission on Drug Policy 2015, 5). It also shows that drug policy is an area in which

104 It is important to note that these recommendations were shaped by the ideas and proposals of the experts and other professionals who participated in our workshops in Cali and Pereira in November 2018.

scientific evidence and public health principles have played a limited role, with devastating consequences for the supposed objectives of the international drug control system: the well-being of all humankind (Csete et al. 2016, 1432).

In Colombia, the legal and policy framework on the right to health contains every possibility for the support and care required by these two populations; however, the reality of untreated pain experienced by both groups, more so in some cities than others, stands in stark contrast to these written provisions.

The dual nature of opioid medicines—at once controlled and essential—creates a paradox in practice, since health systems, following the guidelines of the World Health Organization, require that such substances be made available to and accessible by those who need them, while the international drug control regime, particularly the International Narcotics Control Board, requires that governments take steps to control these substances and their derivatives.

We can conclude that in Colombia, there remains a critical shortage of evidence-based treatment for people with psychoactive substance use disorders. In addition, there is no consolidated information on the availability or quality of specialized treatment for individuals who use heroin. In other words, despite a broad legal framework on the issue, there are still significant barriers impeding this population's effective enjoyment of the right to health.

Meanwhile, there is a dearth of palliative care services in Colombia. This situation will only worsen over time, for as people's life expectancy increases and the burden of chronic and debilitating diseases also grows, the need for such care will increase. The Constitutional Court has begun to identify the right to palliative care as part of the rights to health and to dignity, but the public's general lack of awareness of this possibility means that patients are not demanding such care. This, together with the lack of specialized training among health professionals, results in few practitioners trained to meet the demand for palliative care and opioid medicines.

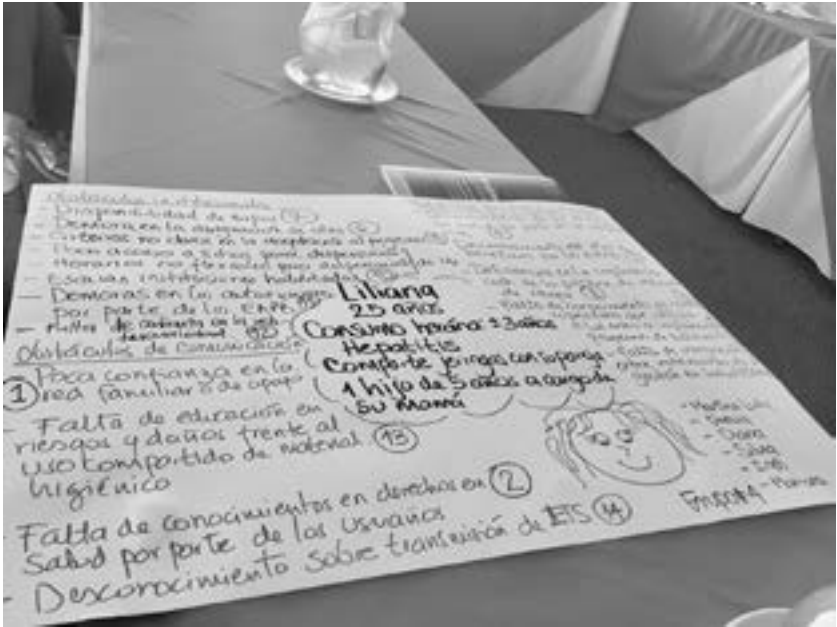
In this sense, the Constitutional Court's jurisprudence has helped establish and position the notion of the right to health within the framework of a system that faces numerous barriers in its implementation and that often fails to fulfill its true aim, which is to ensure comprehensive health care for all Colombians. The court has played an important role in managing conflicts between patients and health system actors and,

through its rulings, has unveiled the structural problems within this system that impede the effective guarantee of this fundamental right.

A broad set of legal and policy standards has addressed the issue of psychoactive substance use disorder and seeks to offer a response on behalf of health institutions. Although these standards have evolved over the past twenty years toward a focus on comprehensive care for problematic drug use and have begun to offer a differentiated approach—such as specific policies aimed at injecting drug use—many legal, cultural, and administrative barriers continue to interfere with the comprehensive care prescribed by national policies. Many PWUD in need of treatment have had to resort to litigation in order to enjoy their right to health, which has generated a line of constitutional jurisprudence on the rights of people with drug use disorders. The Constitutional Court's judgments have established that PWUD are subject to special protection and that the state, through its health system, is obligated to provide them with comprehensive care.

The court's jurisprudence on access to treatment for psychoactive substance use disorders has shed light on the barriers faced by people who use drugs when trying to seek protection of their right to health before actors in the health system, particularly EAPBs. While many of the barriers highlighted by the court are related to structural weaknesses that affect all health care users, not just those who use drugs, they reveal the stigma and discrimination experienced by PWUD, whom health service providers frequently view as undeserving of care. The court's recognition of PWUD as subjects of special protection, together with its pressure on health entities to ensure that they receive comprehensive care, has slowly contributed to the dismantling of some of these barriers.

The Colombian government's obsession with controlling drugs, and the enormous energy it spends on preventing the diversion of controlled substances, has meant that the availability of these substances for medical needs has become a distant dream for many. Acknowledging this predicament in countries throughout the world, the international drug control system dedicated a chapter of the UNGASS outcome document to the elimination of unnecessary barriers and to ensuring greater access to controlled substances for medical purposes, especially palliative care. Although Colombia is not the most extreme example of restricted access to these substances, much remains to be done in the country to quash myths, promote correct interpretations of the law, and educate doctors



Picture 1. Brainstorming notes from civil society workshop

and patients so that they abandon their fear of opioids when such substances are needed at the end of life. Doing so is an ethical duty of both the medical profession and the state as the guarantor of the fundamental rights to life, health, and freedom from cruel and inhuman treatment.

In addition to documenting barriers, our research uncovered numerous experiences of civil society communities committed to supporting patients and improving the quality of life of patients and their families. Thus, the recommendations presented below are based in part on the proposals of these communities, and it is our hope that our recommendations engender further processes that involve their active participation. In our workshops with these individuals, we led an activity to create “buses of change,”¹⁰⁵ with practical ideas that can feasibly be implemented. For example, in Cali, participants suggested that departmental health authorities create palliative care brigades that travel throughout the department to support palliative care patients and to train doctors and nurses in each town and city. In Pereira, they identified the lack of rights awareness

105 The “buses of change” exercise encouraged participants to ideate, through collective thinking, pathways for change that can improve access to these specific health services.

among people who use psychoactive substances as a key barrier to access, proposing the creation of tools to communicate these rights in institutional and community settings where these individuals and their families are present (picture 2). These ideas reflect the creative and proactive potential of these professionals and should be capitalized on by authorities in order to better implement Colombia's laws.

Below, we present several policy recommendations. Our ultimate goal is for this book to prompt the changes necessary to put an end to avoidable suffering. First, we present overarching recommendations with regard to Colombia's health system and drug control system; second, we offer specific recommendations aimed at strengthening palliative care throughout the country and in the five cities of focus; lastly, we offer recommendations centering on the case of people who use heroin and are in need of treatment.

Overarching Recommendations

To the Colombian Health System

As discussed in chapters two and three, the lack of good-quality accredited services is a key barrier. This stems from two main factors: the lack of trained professionals in each of the two fields and the lack of affiliation agreements between EAPBs and the IPSs that do have such professionals. In practice, this can be seen in the health system's cumbersome and confusing processes that patients must navigate when trying to seek relief for their symptoms. Moreover, the Special Registry of Health Service Providers is not up to date, making it difficult to determine which IPSs are accredited to provide services in each city. The Ministry of Health should more carefully update this registry.

Regarding the first issue—that of education—we recommend that palliative care education be incorporated into the curricula of schools of medicine, social work, psychiatry, psychology, and nursing. While this may present a challenge with regard to universities' autonomy, education oversight authorities, together with relevant civil society actors, should advocate before universities to sensitize them on this need. In terms of palliative care, the Colombian Network on Education in Palliative Care is already undertaking such an effort, which Colombia's Ministry of Health should endorse and take part in.

At the time of writing this book, Colombia's Congress was considering a bill to include a mandatory course on palliative care in Colombian schools of medicine, psychology, social work, and nursing. It is critical that such legislative initiatives involve the participation of universities and relevant professional associations in order to ensure that universities' autonomy in decision making does not become an impediment to the goal of universalizing palliative care education.

In terms of training, it is important to prepare not only the new generation of health practitioners but also those who are already providing care. In most cities, sufficiently qualified health workers are scarce, their treatment of patients and family members is often unsympathetic, and training programs continue to be plagued by prejudices toward opioids, the end of life, and addiction. Professional associations can play a key role in sensitizing health workers and offering continuing education in this area. Regarding care for PWUD, there are no professional associations involved in the issue of drug dependence to the same extent as for palliative care. Here, it is important to capitalize on networks of listening centers, community programs, and professionals with experience working in methadone programs in order to shape training efforts.

Concerning the second issue—that of EAPB-IPS relationships—it is urgent that EAPBs update their affiliation agreements with IPSs to ensure that they incorporate the services required under Law 1733 and Law 1566. In this regard, local health authorities have a preventive job to do, which involves encouraging EAPBs to establish affiliations with these service providers. Local health authorities also have a surveillance and control responsibility, as does the Superintendence of Health, to ensure that EAPBs fulfill this obligation toward patients. Lastly, given that the supply of these services is unlikely to meet demand in the near future, it is important to sensitize the Ombudsman's Office on the need to offer legal representation, where necessary, to patients wishing to file health-related *tutelas* (writs of constitutional protection). Moreover, the Ministry of Health and regional health authorities should fulfill their function as regulatory entities for health policy and should conduct more educational outreach at the regional level.

Meanwhile, even when service providers show an interest in dispensing opioids, the dual accreditation requirements—one for registering as a specialized provider and one for registering as a pharmacy—act as a disincentive to dispensing opioids. There is clearly a need for a facility that

provides palliative care or that runs a methadone program to also be able to dispense opioid medicines. One solution is to unify the two accreditation process; however, it is important that such unification ultimately be aimed at improving services for patients and not making requirements even more cumbersome for providers wishing to offer palliative care and treatment for drug use disorders. To this end, the Ministry of Health should play an active role in aligning the accreditation process with actual need, taking into account the suggestions of professional associations and community centers.

To Opioid Control Mechanisms

Our main recommendation to national authorities has to do with the principal barrier to opioid availability: the mechanism currently used to estimate the purchase of these medicines and their subsequent distribution across the country. This mechanism calculates future purchases based on historical consumption levels, but due to the range of difficulties involved in opioid prescribing, these historical levels are generally low, especially in departments with few service providers and practitioners. This begets a vicious cycle of underestimation in which estimates are based on historical consumption levels that fail to satisfy patients' need for pain relief. To put an end to this cycle, the government must change the way it calculates its opioid purchases, taking into account epidemiological, demographic, and heroin use variables.

In all five cities, we found that the Regional Narcotics Funds do not believe there to be opioid shortages. However, our interviews with patients revealed not only an undersupply but also a lack of accessibility. The government's estimates of opioid needs should be a participatory process that incorporates all relevant stakeholders, including palliative care providers and volunteers, methadone and harm reduction programs, and, of course, EAPBs. Lastly, it is important to document the best practices of IPSs, such as purchasing reserve stocks of medicines, and to encourage other service providers to adopt these practices.

As we have explained, Colombian law is reasonable in its aim to regulate access to controlled medicines. Most of the problems concerning access to opioids are due to restrictive or excessive interpretations of the law. This highlights the need to continuously educate Regional Narcotics Funds, EAPBs, and departmental secretariats of health on what exactly the law requires and what actions are deemed excessive. Such educational

efforts should be aimed in particular at raising staff members' awareness of the fact that overly restrictive interpretations lead to violations of core aspects of the right to health of vulnerable populations, such as people who use heroin and people suffering from pain at the end of life.

In light of staff turnover, such educational efforts should be periodic in order to uphold consistent standards that guarantee the availability of and access to opioids in accordance with the needs of each region. This is especially critical with regard to the mistaken belief that prescriptions must be filled in the same department in which they were issued, as well as the belief that only psychiatrists and anesthesiologists may prescribe opioids.

Moreover, in the area of methadone maintenance therapy, it came as a surprise to the professionals we interviewed that the Palliative Care Law requires each department in the country to have at least one accredited pharmacy that offers round-the-clock service (see Universidad de La Sabana 2019). We call on health and drug regulatory authorities to ensure that this standard is enforced and to advocate for the law's expansion to address treatment for people who use heroin.

In the future, the National Narcotics Fund and Regional Narcotics Funds could benefit from the implementation of an online prescription system, which would eliminate several of the barriers currently standing in the way of opioid prescribing—for example, the fact that facilities must purchase official prescription pads and sometimes run out of them—and would also offer greater security for opioid prescribing and for information sharing among EAPBs, IPSs, and national and departmental authorities.

Sometimes, patients do not use all of their prescriptions, and while a protocol exists for returning surplus medicines, many patients and practitioners are unfamiliar with the process, meaning that medicines end up in the trash, which is a waste in light of the scale of need. We recommend that Regional Narcotics Funds, in collaboration with EAPBs, design a protocol for creating municipal or departmental medicine banks that IPSs and patients can turn to in cases where they have been unable, for whatever reason, to gain access to opioids.

Opioids come in various forms to address all types of need, and thus it is important that professional associations engage in constant dialogue with drug regulatory authorities in order to identify the forms of opioids that are needed in the country. For example, for maintenance therapy,

liquid methadone can be useful, as can liquid buprenorphine, which is currently not available in Colombia. The Ministry of Health, the National Food and Drug Surveillance Institute, and the National Narcotics Fund should take steps to incorporate all necessary forms of opioids into the country's catalogue of medicines.

It goes without saying that the measures we recommend here implicate a financial cost—but it is critical that health authorities acknowledge the currently disproportionate level of public spending on drug policy, which is evident not just in Colombia but around the world. While the world's governments spend US\$100 billion on enforcing international drug controls, just US\$145 million is needed to close the opioid access abyss for low- and middle-income countries (Knaul et al. 2018, 4).

Recommendations concerning Pain Relief in Palliative Care

Colombia's Palliative Care Law provides legal guarantees that should be reflected in universal access to palliative care and opioid medicines. One of the key barriers to making this a reality is the failings of the education system, for the curricula of schools of medicine, nursing, and psychology rarely address the topic of palliative care. Even more neglected in these curricula is the use of opioids. This results in a health system with a high level of avoidable human suffering due to practitioners' lack of training on these issues.

For this reason, our principal recommendation is that palliative care education be incorporated into medical school training and that collaborative alliances of professional associations, the Ministry of Health, and the Ministry of Education play a central role in this effort.

In addition, many health professionals have acquired medical specialties abroad, but they are unable to validate their diplomas in Colombia. The government must take steps to ensure that such degrees can be validated in the country. Given that trained practitioners are still in short supply throughout the country, we also encourage the Ministry of Health to implement strategies such as telemedicine in order to attend to populations in areas where there are no specialists.

With regard to improving access to and the availability of opioids, the palliative care professionals we interviewed were emphatic in stating that all of the medications they use in palliative care should be included

in the Health Benefits Plan, since some of these medicines—particularly the patches—are currently excluded from the plan due to their high cost, placing burdens and delays on patients that lead to avoidable suffering.

In palliative care, the subcutaneous administration route is the second most popular administration method (the first being oral administration), as it is an easy method for both patients and their caregivers. Thus, authorities should ensure that the country is equipped with the supplies needed for this administration route, and EAPBs should guarantee that these materials are delivered without barriers to patients who need them.

Lastly, the Inter-American Convention on Protecting the Human Rights of Older Persons contains right-to-health provisions that relate to palliative care and access to opioid medicines. To protect this especially vulnerable population of patients in need of palliative care, which is rapidly growing throughout the country, the Colombian government should ratify this convention.

Recommendations concerning Pain Relief for People Who Use Heroin

The absence of a comprehensive response to the situation of people who use heroin prevents them from fully enjoying their human rights and deepens their marginalization. It is a harsh reflection of the distance between the Colombian state and the country's most vulnerable.

With regard to the availability of medicines for this population, one urgent priority is for the Ministry of Health and departmental health authorities to guarantee the availability of naloxone in first-level health facilities for community peers, family members, and support networks. The chance to save the lives of PWUD often depends on these individuals.

In addition, it is crucial that methadone be available and accessible in all levels of health facilities in cities with significant heroin consumption and that emergency room health professionals receive periodic training in how to identify and treat withdrawal symptoms with this medicine, even in cases where patients visit the emergency room for general health problems unrelated to their drug use. Methadone should also be available in detention centers.

In general, it is critical that treatment programs embrace a differentiated approach that adapts to the specific needs of individuals, that they

abandon the idea of abstinence as the short-term and ultimate goal, and that they adopt a comprehensive focus that goes beyond substance use.

Methadone maintenance programs—both those already in operation and those under development—should involve the participation of and consultation with the target population in order to ensure that they cater to the schedules, dynamics, and conditions of their clients. The creation of such spaces for dialogue builds trust among patients and also helps identify areas for improvement, unnecessary rules, shortcomings in the mechanisms for dispensing medications, and the needs of patients beyond methadone. Moreover, each city should have an accurate estimate of the population in need and, relying on this baseline, increase its number of services. This would help reduce the long wait lists that negatively affect individuals' ability to access treatment by causing them to lose momentum.

Furthermore, these programs should strengthen their comprehensive care approach, for some of them focus solely on dispensing medicines, which—though necessary for care—does not help resolve the broader problems of this vulnerable population, particularly in cases where patients present a dual pathology of drug use and mental illness. Such programs should incorporate psychosocial support into their treatment plans and connect it to programs on employment, education, and health.

It is also important that programs adopt differentiated approaches for key populations who are even more invisible than the overall PWUD population—for example, women who use drugs and trans people who use drugs. These two groups face strong discrimination within drug-using circles and are often denied access to treatment. When they are admitted to such programs, there is no differentiated approach to their care.

Cities' social and health care services should have differentiated protocols for people in street situations, which could support individuals in filling out their *cédula* applications, in registering for health care, and in making appointments to facilitate the pathway to treatment. This goes hand in hand with the need to strengthen—at the institutional, financial, and human resource levels—low-threshold programs.

Local health authorities should continue ongoing efforts to sensitize the police force so that officers are educated in the constitutional protections and special protection awarded to these individuals and so that they abandon harmful practices, such as the seizure of hygienic injecting materials and personal doses of heroin. Protocols for denouncing police harassment and abuse toward PWUD, especially those who live on the

street, should also be established. Finally, it is critical that the state make evidence-based drug use disorder treatment available to people who are deprived of their liberty.

A Future Research Agenda on Colombia's Response to Pain Relief

During the course of our investigation, we came across several issues that called for a deeper understanding in terms of the impacts of the state's failure to fulfill the demand for opioid medicines and the health system's shortcomings in attending to people who use drugs and those at the end of life. Although we were unable to delve into these issues in this book, we believe that they are important to address as part of a future research agenda. Some of them include the following:

While some research has been done on women's role in the care economy and how it contributes to household income,¹⁰⁶ there are still no quantitative studies of the emotional, economic, and professional price that women must pay when having to assume the care of a chronically or terminally ill relative. As demonstrated in chapter three, this task is usually assumed by a woman within the family who does not have the possibility of generating income, which means that the responsibility of caregiving even further exacerbates the barriers to achieving her life goals. The feminist movement's work on the care economy has yet to incorporate issues regarding care at the end of life, and this is an issue requiring further exploration in the country.

With regard to heroin use, we discovered one serious failing, which is the lack of maintenance therapy in prisons. This means that PWUD who are incarcerated must quit "cold turkey." Many of them told us about their suicidal feelings as a result of the lack of methadone to alleviate their withdrawal symptoms. In general, PWUD who live on the street are susceptible to being deprived of their liberty because of the need to engage in criminal activities around the consumption of a drug that is illegal. Thus, for people who use heroin, going to prison is marked by suffering similar to torture due to the lack of opioid medicines in these facilities. Sentence T-388 of the Constitutional Court declared a "an unconstitutional state of affairs in [Colombia's] prisons" in light of the range of problems present in

106 See <https://mesaintersectorialdeeeconomiaelcuidadocolombia.word-press.com>.

these facilities, including the violation of incarcerated individuals' right to health.¹⁰⁷ To remedy this unconstitutional state of affairs, it is important to include health care for PWUD within the relevant research and policy advocacy agendas.

Moreover, as we described in chapter two, women who use drugs experience one of the most dire cases of marginalization, for they are already a marginalized population on account of their sex. Of the scarce treatment programs that do exist, many refuse to admit women patients, which is an openly discriminatory practice in addition to being founded on chauvinist notions. Additionally, the treatment centers that do admit women lack differentiated models of care that take into account women's specific needs. This is another issue that requires further research.

Lastly, it is important to explore the impacts of the war on drugs on the right to health. In the name of wiping out narcotic substances, the government is deepening the stigmatization of opioids and of those who, for one reason or another, need them. For these individuals, the worst of all worlds has emerged thanks to an intensification of the barriers that make "a drug-free world" today's harsh reality.

We hope that this book constitutes the first step in promoting collaboration between, on the one hand, health professionals and social science practitioners who work in defense of the rights of people facing the end of life and, on the other, those who advocate for the rights of people who use drugs. We also hope that it fosters a sense of solidarity between these two populations that allows them to see how they have both been victimized by the war against drugs and to work together not just for greater access to pain medicines but also for drug policy reform centered on human rights and public health.

As highlighted at the beginning of the book, these populations, which seem so different on the surface, have more in common than one might think: they are both invisible to the health system, they both suffer from the lack of adequately trained health professionals to deal with the end of life and heroin dependence, they both seek health services during moments of extreme vulnerability, and they are both populations for whom opioids are essential but not sufficient. In addition to opioids, we need social, cultural, and health systems that acknowledge the suffering associated with death, the end of life, problematic drug use, and treatment

107 Corte Constitucional, Sentencia T-388 de 2013, June 28, 2013.

for drug dependence. Such an institutional and social transformation requires that we be willing to embrace the battle and transformation. These shared traits reveal the possibility of building alliances to alleviate suffering and guarantee the right to health for the two populations addressed here. It is our hope that this book contributes to such a conversation.

GLOSSARY

CAD: Drug addiction center (*centro de atención a la drogadicción*); specialized health entity created by Law 1566 of 2012

Derecho de petición: Literally “the right of petition,” or the right of any person to file a request for information before a public entity or a private entity that carries out public functions, and to receive a timely response to that request; enshrined in article 23 of Colombia’s Constitution

EAPB: Health benefits management company (*entidad administradora de planes de beneficios*)

EPS: Health promoting entity (*entidad promotora de salud*)

ESE: Public health care institution (*empresa social del estado*)

IPS: Health service provider institution (*institución prestador de salud*)

Narcotic: A chemical substance that produces stupor, coma, or insensibility to pain

Opiate: A narcotic substance derived from opium poppy

Opioid: A generic term applied to alkaloids derived from opium poppy, their synthetic analogues, and compounds synthesized in the body; they interact with specific receptors in the brain, have the capacity to relieve pain, and produce a sensation of well-being (euphoria)

Psychoactive substance use disorder: According to the *International Statistical Classification of Diseases and Related Health Problems* (10th edition), a cluster of physiological, behavioral, and cognitive phenomena in which the use of a psychoactive substance takes on a much higher priority for a given individual than other behaviors

PWUD: People who use drugs

SDGs: Sustainable Development Goals

Tutela: A type of lawsuit that may be filed by any person before any judge in the country in order to request the protection of their fundamental rights; enshrined in article 86 of Colombia's Constitution

UNAIDS: Joint United Nations Programme on HIV/AIDS

UNGASS: United Nations General Assembly's Special Session on the World Drug Problem, held in 2016

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ANNEX

List of Opioid Medicines in Colombia

Name	Medicines subject to special control	Medicines placed under state monopoly	Used in palliative care?	Used in maintenance therapy?	Included in Health Benefits Plan?
Fentanyl (various forms)	X		Yes	No	No
Oxycodone (various forms)	X		Yes	No	No
Tapentadol (various forms)	X		Yes	No	No
Hydromorphone (various forms)		X	Yes	No	Yes
Meperidine (various forms)		X	No	No	Yes
Methadone (10 mg or 40mg tablet only)		X	Yes	Yes	Yes
Morphine (oral solution or injection)		X	Yes	No	Yes

SOURCE: Ministry of Health; National Narcotics Fund

Medicines subject to special control: Medicines whose importation and distribution are under special controls exercised by the National Narcotics Fund.

Medicines placed under state monopoly: Medicines that are manufactured domestically or imported and whose distribution is the exclusive domain of the state, as fulfilled by the National Narcotics Fund.

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The suffering and pain experienced by people

with terminal illnesses and people with heroin use disorder can be alleviated through opioids. At the same time, the enforcement of international drug control treaties means that these medicines are subjected to strict controls that create excessive red tape and contribute to a generalized fear among patients and health professionals concerning these medicines' use. Although many opioids are included in the World Health Organization's list of essential medicines, the fact that they are controlled substances means that in practice, the right to health of these two populations is often violated.

This book offers a diagnosis of five Colombian cities with regard to the barriers that both populations—patients at the end of life and individuals with heroin use disorder—face when trying to access opioids. The hurdles they encounter can be grouped into four categories: (i) structural failings of the Colombian health system; (ii) a lack of institutional capacity to maintain sufficient opioid stocks in small and medium cities; (iii) a lack of specialized training among health professionals in small and medium cities on the issues of palliative care and psychoactive substance use disorders; and (iv) stigma surrounding opioids and the people who use them.

Analyzing the enjoyment of the right to health among these two groups of people would seem ill advised, for what could they and the health care they receive possibly have in common? However, this book argues that someone facing the end of life and someone with a heroin use disorder actually face similar challenges: they are both in need of the same controlled substances; they both require interdisciplinary treatment that extends beyond opioids; they both seek health services during moments of extreme vulnerability; and they are both often treated negligently by health systems that are ill equipped to handle death and drug dependence.

This book seeks to facilitate linkages between discussions on the right to health and discussions on drug policy reform. The populations we talk about here are the ones most in need of a change whereby drug control measures cease to stand in the way of a life free from pain.

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