

# Palliative Care

A Human Rights  
Approach to  
Health Care

*Isabel Pereira*



**WORKING PAPER 5**

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# **Palliative Care** **A Human Rights** **Approach** **to Health Care**

*Isabel Pereira*

## **Working Paper 5**

PALLIATIVE CARE:

A HUMAN RIGHTS APPROACH TO HEALTH CARE

This report was originally published in Spanish, under the title *Cuidados paliativos: El abordaje de la atención en salud desde un enfoque de derechos humanos*, by Dejusticia, Bogotá, August 2016.

ISBN: 978-958-5441-37-8    Digital Edition

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Translation & Copy Editing: Morgan Stoffregen

Layout: Marta Rojas

Cover: Alejandro Ospina

First English Edition:

Bogotá, Colombia, May 2018

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## **Abbreviations**

Convention on Older Persons	Inter-American Convention on Protecting the Human Rights of Older Persons
ECLAC	Economic Commission for Latin America and the Caribbean
OAS	Organization of American States
UNGASS	United Nations General Assembly Special Session on Drugs
WHO	World Health Organization



## Introduction

This report compiles the results of a research project aimed at describing the current palliative care situation in eight Latin American countries. The project's general objective—to raise awareness and influence public policy around the need to approach palliative care from a human rights perspective—was achieved through rapprochement among professionals from various fields in the region, which in and of itself is a key step forward in terms of bringing together communities that defend patients' rights with communities that advocate a drug policy embracing a public health focus.

We hope that this diagnostic report is useful for professional associations, health professionals, patients' rights advocates, drug policy reform activists, and decision makers, who can rely on its findings to better integrate palliative care into general health services and to use human rights language to promote public policy reform and guarantee the human rights of those in the Americas who suffer from severe and chronic pain.

Dejusticia's research team is especially grateful to the palliative care professionals and experts who advised the project: Liliana de Lima, Marta Ximena León, and Diederik Lohman. We also wish to thank two professionals in Colombia—Cesar Consuegra from Institución Cuidarte and Juan Carlos Hernández from Hospice Presentes—who not only shared their knowledge and experience but also put us in touch with patients and their families. Without them, it would have been impossible to learn about and understand the realities and barriers that palliative care professionals face on a daily basis.

A fundamental component of this research is the information provided by doctors in each of the eight countries analyzed. We are grateful to each and every one of them for allowing us to interview them, for

reviewing the final draft, and for clarifying particular concepts and challenges related to their countries' health systems. We also thank them for their willingness, expressed from the start, to continue supporting the development of palliative care throughout the region. We also thank Dejusticia's administrative team, which was indispensable for allowing us to conduct our research and advocacy work.

This report was written by Isabel Pereira, researcher at the Center for the Study of Law, Justice and Society (Dejusticia). The report was reviewed by Diana Guarnizo and Sergio Chaparro, researchers at Dejusticia, and Liliana de Lima, executive director of the International Association for Hospice and Palliative Care. The report received financial support from the Open Society Foundations.

This edition is an English translation of *Cuidados paliativos: El abordaje de la atención en salud desde un enfoque de derechos humanos*, published by Dejusticia in August 2016; the data was not updated for the English translation.

## I. PALLIATIVE CARE: A HUMAN RIGHTS APPROACH TO HEALTH CARE

The field of palliative care has begun to make linkages to both the human rights discourse and discussions on the need for global drug policy reform. With regard to the former, expert coalitions, the World Health Organization (WHO), and civil society organizations advocating for the right to health and other human rights have recently brought attention to palliative care in international forums, emphasizing that palliative care not only offers dignity to patients in situations of suffering but also deserves recognition as a human right under international law. Advances in this regard can be seen in a 2013 report of the United Nations Special Rapporteur on Torture<sup>1</sup> and in Resolution 67.19 of the World Health Assembly, entitled “Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course.”<sup>2</sup>

With regard to drug policy reform, civil society organizations and some governments have brought attention to the fact that global drug policy, particularly the control of opioids, has left millions of people around the world in situations of avoidable suffering (Global Commission on Drug Policy 2015). The United Nations High Commissioner for Human Rights, in his report to the Human Rights Council submitted in September 2015,<sup>3</sup> highlighted the impact of the global drug problem on the

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- 1 United Nations, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, Juan E. Méndez, UN Doc. A/HRC/22/53 (2013), para. 86.
  - 2 World Health Organization, *Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course*, 67th World Health Assembly Resolution WHA67.19 (2014).
  - 3 United Nations, *Study on the Impact of the World Drug Problem on the Enjoyment of Human Rights: Report of the United Nations High Commis-*

enjoyment of human rights, particularly the right to health. The report reveals how drug policies have constituted an obstacle to pain management and argues that the implementation of drug controls should incorporate a human rights focus in order to prevent injustices to people in need of relieving symptoms associated with illness.

In 2015, the Americas witnessed important progress in this area with the approval of the Inter-American Convention on Protecting the Human Rights of Older Persons (hereinafter the “Convention on Older Persons”), which establishes specific state obligations regarding the integration of palliative care into health systems and into care for the elderly. In light of this improving context for palliative care at the global level, this report analyzes the palliative care situation in eight Latin American countries: Argentina, Chile, Colombia, Costa Rica, El Salvador, Guatemala, Panama, and Uruguay. To this end, the first section of the report provides a conceptual framework and explores the context of palliative care in Latin America, including its current challenges. The second section explains the aims of this research, its analytical scope, and its sources. The third section offers a diagnosis of each of the eight countries under study. The fourth and final section presents a series of recommendations aimed at public policy reform, advocacy efforts, and interactions among various sectors.

## **What Is Palliative Care? What Constitutes a Palliative Care Model and Its Integration into Health Care?**

Palliative care is a medical approach that consists of providing due attention to the patient’s pain and suffering, independent of his or her prognosis. According to WHO, palliative care “is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering” (WHO 2018). Palliative care may be applied to any physical, psychosocial, or spiritual problem linked to the treatment of an illness threatening the patient’s life, and it may be applied from the moment of diagnosis until the end of a patient’s life.

According to WHO, palliative care does the following:

- provides relief from pain and other distressing symptoms;

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*sioner for Human Rights*, UN Doc. A/HRC/30/65 (2015), paras. 32, 33.

- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (WHO 2018)

The severe pain suffered by patients with terminal or chronic illnesses, as well as by those who have had accidents or surgeries, not only alters their quality of life but also can have negative effects on their mental health, mobility, livelihoods, and immune system. The process of ageing, for its part, can also sometimes create degenerative conditions that cause pain and suffering for certain individuals.

Palliative care, when integrated into general health care, has enormous potential to guarantee human rights, particularly the right to dignity of individuals suffering from chronic or terminal illnesses. Nonetheless, the management of certain illnesses from a palliative care perspective is still in its infancy at the global and regional levels. This is due to three factors. First, the traditional focus of the right to health has been on curative aspects. Second, palliative care as a medical practice and specialty is a relatively recent development. And finally, people who require palliative care—those suffering from life-threatening or incurable conditions—are among society’s most vulnerable; often, neither they nor their families have the capacity or time to advocate for their needs. In other words, those suffering from pain lack the voice to wave the banner of palliative care.

With regard to the first aspect, modern biomedical science has centered its attention and efforts on curing illnesses, which drives its focus away from how patients experience their illness and its symptoms (Kleinman 1988, p. xiv). Del Río and Palma (2007) note that the modern medical

approach centers on “prolonging life expectancies among the population, rather than ensuring the quality of life as an objective in itself” and argue that modern medicine’s curative obsession has led to “therapeutic obstinacy” (p. 1). This obsession is further strengthened by society’s distance from the reality of death and a general unwillingness to acknowledge the realities of pain and suffering. Thus, both doctors and patients hold on to curative possibilities as the only hope (Kleinman 1988, p. 142).

In the 1960s, the hospice movement emerged in the United Kingdom in response to the growing population of terminally ill patients and older persons and in clear resistance to this curative medical approach. The movement sought to reclaim the “care” dimension of medicine, with the express objective of improving the quality of life of the terminally ill. For the medical profession, this meant reassessing its objective, recalling that medicine is fundamentally about providing support to the patient, and recognizing physicians’ impotence with regard to death (Del Río and Palma 2007, pp. 1–2). As Kleinman writes, “We must begin with the premise that chronic disease by definition cannot be cured, that indeed the quest for cure is a dangerous myth that serves patient and practitioner poorly . . . The practitioner must relinquish the myth of cure” (1988, p. 229).

To reframe the relationship between illness and death, both health professionals and patients needed a new language and a new way of working that would integrate a focus on symptoms and whose main objective would center on care that improves the patient’s quality of life and network of support. Championing these principles, the hospice movement was established in 1967, the year that St. Christopher’s Hospice was founded by Cicely Saunders (St. Christopher’s n.d.).

The second factor behind palliative care’s incipency at the global and regional levels has to do with its belated inclusion in the medical discipline. It was not until 1987 that palliative medicine was recognized as a subspecialty of medicine in the United Kingdom. Since then, this subspecialty has experienced accelerated growth, as reflected in scientific academic advances, the expansion of palliative care units around the world, and the increase in health professionals with specialized training in palliative care. Global and regional health bodies (such as WHO and the Pan American Health Organization) have also formally recognized palliative care as a discipline and, since the 1980s, have begun to formulate definitions and practical guidelines on the topic (Del Río and Palma 2007, p. 2). The rapid growth of palliative care is evidence, then, of the need to

return our focus toward suffering and toward patient care, regardless of a patient's prognosis. For Kleinman, this transformation in medicine necessitates changes in medical training that raise health professionals' awareness of psychosocial and cultural aspects of illnesses, instead of focusing focus merely on biological aspects and the myth of the cure (1988, pp. 254–256).

The accelerated development of palliative care at the global level recently resulted in a key milestone: the approval of Resolution 67.19, entitled “Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course,” by the WHO General Assembly during its sixty-seventh session in 2014. The resolution recognizes the need to integrate palliative care services into comprehensive health services in such a way that improves patients' quality of life. The failure to include palliative care in this manner has meant that, today, access to such care is highly inequitable, with most palliative care units concentrated in developed countries and in large capitals, with limited or almost nonexistent access in developing countries and rural areas. These shortcomings also affect patients' rights to receive adequate information on their condition and to participate in decision-making processes regarding their health.

Among other things, the provision of palliative care requires that licit drugs subject to international control be made available to patients who need them. To do this, countries must be able to estimate the quantity of opioid analgesics needed to satisfy the demands of patients suffering from pain. Nonetheless, the focus on preventing the diversion of controlled substances for illicit purposes undermines the availability of and access to these substances for medical purposes. Resolution 67.19 calls on relevant actors within the United Nations system to ensure that oversight activities do not become a barrier to accessing these substances for medical use.<sup>4</sup>

Meanwhile, the effective integration of palliative care contributes broadly to the aims of social protection by meeting the pain management needs of patients. In this sense, systems of social protection are still lagging behind in terms of acknowledging the processes of sickness and death as moments deserving of guarantees, protection, and intervention.<sup>5</sup> Effectively incorporating palliative care into the general health system

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4 World Health Organization, Resolution 67.19, *supra* note 2.

5 For a systemic vision of social protection, see Cecchini, Filgueira, and Robles (2013, p. 10).

requires focusing efforts on four lines of action within the public health model (Stjernsward, Foley, and Ferris 2007):

### **Policy**

- Laws that recognize and define palliative care as part of the health system
- National standards on palliative care
- Clinical guidelines and protocols
- Establishment of palliative care as a recognized specialty or subspecialty of medicine
- Regulations that provide appropriate licensing provisions for palliative care and its providers
- National strategy for the implementation of palliative care

### **Education**

- Basic palliative care training for all health professionals
- Intermediate palliative care training for those who regularly treat patients with life-threatening illnesses
- Specialized palliative care training for those who treat patients who require the permanent management of symptoms

### **Drug availability**

- Regulatory model for opioids
- Formulations of available opioids (oral, injectable, etc.)
- Systems for supply and distribution
- Authorized personnel for prescribing opioids

### **Implementation**

- Opinion leaders who raise awareness of the issue
- Trainers with the ability to teach
- Strategic and business plans
- Standardized guidelines and measures

## **Why Is Palliative Care Necessary?**

The need for palliative care has increased due to two main factors: population ageing and the increased incidence of noncommunicable diseases.<sup>6</sup>

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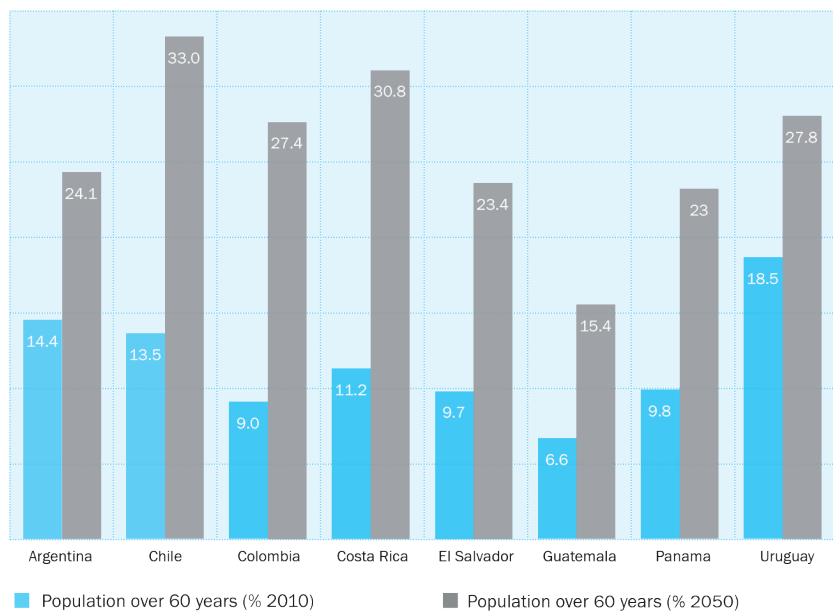
<sup>6</sup> The World Health Organization (2013a) defines noncommunicable diseases as “diseases of long duration and generally slow progression” and distinguishes four types: (i) cardiovascular diseases; (ii) cancer; (iii) chronic respiratory diseases; and (iv) diabetes.



In terms of population ageing, the demographic profile of the Americas, like that of the globe, is experiencing drastic changes that directly affect health care needs. Gradually and consistently, the populations of the countries studied here are transforming from ones in which less than 10% of the population was over the age of sixty in 2010 to ones in which 25.4% of the population will be in this age group by 2050 (Economic Commission for Latin America and the Caribbean 2015, p. 36). Although measures for disease prevention and healthy life habits for active ageing are being promoted, degenerative disease in the adult population remains a reality—one that requires comprehensive care with a focus on palliative care. The demographic transitions of the eight countries studied here show that, in most cases, the population of older persons will double over the next forty years (see graph 1).

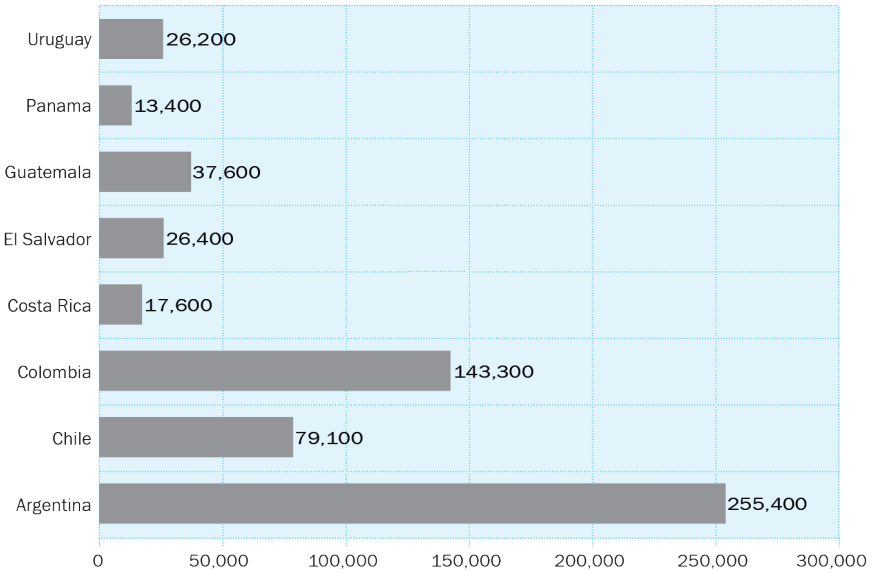
According to WHO, noncommunicable diseases are responsible for 60% of global deaths, of which 80% occur in middle- and low-income countries (World Health Organization 2008). It is estimated that twenty million people worldwide—of whom 6% are children and 13% live in Latin America—are in need of palliative care (Worldwide Palliative Care

**GRAPH 1**  
**Demographic transitions**



**SOURCE:** Economic Commission for Latin America and the Caribbean (2015)

**GRAPH 2**  
**Total deaths caused by noncommunicable diseases (2012)**



**SOURCE:** World Health Organization (2013)

Alliance and World Health Organization 2014, p. 15). Graph 2 presents data on the number of deaths caused by noncommunicable diseases within the eight countries explored in this report.

According to a recent publication of the Worldwide Hospice Palliative Care Alliance, 34% of individuals in need of palliative care have cancer, 38.4% have cardiovascular disease, and the remainder have illnesses such as HIV/AIDS, diabetes, dementia, and degenerative or chronic diseases. In the Americas, 365 out of every 100,000 adults require palliative care at the end of life (Worldwide Palliative Care Alliance and World Health Organization 2014, pp. 14–15).

**What Barriers Stand in the Way of the Effective Availability of and Access to Palliative Care?**

The fourteen medications most commonly used in palliative care are included in WHO’s Model List of Essential Medicines (World Health Organization 2015). However, 80% of the world’s population lacks adequate access to these medicines, and 90% of their consumption is concentrated in industrialized countries such as Australia, Canada, New Zealand, the United States, and some European countries (Global Commission on

Drug Policy 2015). A 2016 study performed at the global, regional, and national levels found a substantial increase in consumption in North America, Central and Western Europe, and Oceania between 2001 and 2013. During this same period, countries in other regions did not record a significant increase in the use of opioids (Berterame et al. 2016).

The preamble to the 1961 Single Convention on Narcotic Drugs states that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and . . . adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”<sup>7</sup> It is clear that part of the objective of the international drug control system is to ensure that controlled substances are available exclusively for medical use. States’ obligations, which are described in the operative text of the convention, are vague in terms of guaranteeing access to these substances for medical purposes, while the obligations related to these drugs’ control—in terms of mechanisms, procedures, bodies, and penalties—are extensive. Thus, the main aim of the convention, which recognizes the use of narcotic drugs as essential for pain relief, is being overshadowed by efforts to control these substances and prevent their illicit use.

In this regard, WHO has called for ensuring an adequate balance in national drug control policies and has issued guidance<sup>8</sup> to help governments improve the availability of and access to medicines that have an indispensable therapeutic value, such as opioids. The principle of “balance” represents a dual obligation imposed on states by the 1961 convention. To guarantee this principle, drug policies must also incorporate the concerns of sectors that influence the availability and use of controlled substances (World Health Organization 2011, p. 11).

In practical terms, patients are often caught in the crossfire between the implementation of the international drug control regime and the exercise of the right to health. At the same time, health professionals face regulatory and institutional barriers to prescribing palliative care medicines when trying to access effective methods to alleviate their patients’ pain.

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<sup>7</sup> United Nations, Single Convention on Narcotic Drugs (1961).

<sup>8</sup> This guidance includes recommendations on the content of drug control legislation and policies, authorities and their role in the system, policy planning for availability and accessibility, health care professionals, estimates and statistics, and procurement. See World Health Organization (2011, pp. 19–38).

Moreover, the region's health systems do not incorporate a focus on this kind of health need. While social protection systems have undergone transformations at many levels in recent decades—mainly by incorporating human rights guarantees in combination with a welfare focus—very few countries currently embrace social protection that is geared toward the elderly or that includes a palliative care approach for the terminally ill.

While the 1980s and 1990s were characterized by a contraction and decline in terms of progressive social policies, the first decade of the millennium has seen an expansion in state actions to protect and guarantee social rights. These actions include efforts to expand coverage, service networks, and populations served. In 1992, health expenditures in Latin America represented, on average, just 2.7% of public spending. By 2011, this figure gradually increased to 3.9%. Similarly, countries' health care coverage increased from 46.1% of the population in 2002 to 54.4% in 2011 (World Health Organization 2011, pp. 32–34).

Moreover, population ageing, which is still a nascent trend, has not yet been incorporated into public policies; this means that a vulnerable part of the population remains in need of a differentiated approach to care. To this end, the Convention on Older Persons represents an important tool in the region for streamlining the institutionalization of palliative care into health care, thereby contributing to improved quality of life and death through the alleviation of symptoms and suffering associated with ageing and degenerative disease.

The political positioning of older persons' human rights began taking shape in the region in 2011, when the Organization of American States (OAS) established a working group on the protection of the human rights of older persons, which was tasked with drafting a report on the situation of this population throughout the region and exploring the viability of a draft convention. As a result of the working group's effort, in June 2015 OAS member states approved the Inter-American Convention on Protecting the Human Rights of Older Persons—the world's first regional instrument on older persons—establishing specific state obligations regarding human rights and palliative care. The convention represents a major step forward in that it helps overcome the region's normative fragmentation and provides a coherent set of guiding principles for public policy.

As part of its diagnosis of the situation of older persons in the region (Permanent Council of the OAS 2011), the working group shed light on

some previous observations of the Demographic Observatory of Latin America of the Economic Commission for Latin America and the Caribbean (ECLAC):

- In 2010, just 9.7% of the region's population was over sixty years old.
- By 2050, 25.4% of the population (between 180 and 190 million people) is projected to be over sixty years old.
- Between 1950 and 2010, average life expectancy increased from fifty-one to seventy-five years, and it is projected to grow to eighty years by mid-century.

Public policy in the region has developed in a scattered manner, given that population ageing is still an emerging theme. Only in recent decades has the issue been integrated into the frameworks of health systems, social development programs, and care for vulnerable populations. According to ECLAC, in 2011, thirteen countries in the region had laws protecting the human rights of older persons, while ten had constitutional provisions expressly recognizing the rights of older persons.<sup>9</sup> However, legal or constitutional recognition of these rights is not necessarily matched by an improved situation among older persons, since laws and constitutions are often poorly upheld.

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<sup>9</sup> The thirteen countries with specific laws are Brazil, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Paraguay, Peru, the Dominican Republic, and Venezuela. The ten countries with constitutional recognition are Brazil, Costa Rica, Colombia, Bolivia, the Dominican Republic, Honduras, Nicaragua, Panama, Paraguay, and Venezuela. See ECLAC (2011).



## II. RESEARCH

### Objective

Using eight Latin American countries as case studies, this report explores access to palliative care medicines, the impact on the human rights of patients suffering from pain or terminal illnesses, and countries' progress in terms of fulfilling the obligations outlined in the Convention on Older Persons.

We used the following criteria to select the countries of study:

- One-half of the selected countries must be signatories to the Convention on Older Persons and the other half must not.
- The selected countries' level of palliative care development—according to the scale developed by the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012)—must be between 3a and 4b, which allows for an examination of existing services.<sup>1</sup>
- The selected countries must demonstrate a range of positions in international debates and discussions on drug policy and human rights.

Four of the eight countries are signatories to the convention, and four are not. The countries' range of palliative care development is wide, going from countries such as Costa Rica and Colombia, which have an advanced level, to countries such as El Salvador and Guatemala, which have an incipient level. In addition, the countries studied here are diverse with regard to their participation in global debates on drug policy reform.

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<sup>1</sup> For the scale of palliative care development, see Wright et al. (2008).

**TABLE 1**  
**Overview of palliative care in the selected countries**

Country	Population	GDP per capita	Percentage of GDP dedicated to health	Level of palliative care development*	Morphine consumption (mg/capita) (2013)	Score: On a scale from 1 to 5, collaboration between prescribers and regulators (opioids)	Signatory to the Convention on Older Persons?
Argentina	41,446,000	14,715	7.3	4a	7.30	4.0	Yes
Chile	17,620,000	21,030	7.7	4a	2.49	4.0	Yes
Colombia	48,321,000	11,890	6.8	4b	1.49	3.5	No
Costa Rica	4,872,000	13,750	9.9	4b	3.62	5.0	Yes
El Salvador	6,340,000	7,490	6.9	3a	0.31	2.0	No
Guatemala	15,468,000	7,130	6.4	3a	0.04	2.0	No
Panama	3,864,000	19,290	7.2	4a	0.22	3.5	No
Uruguay	3,407,000	18,930	8.8	3a	4.32	3.7	Yes

\* According to the scale developed in the *Atlas of Palliative Care in Latin America*. 3a: palliative care is patchy in scope; 4a: palliative care is in a preliminary phase of integration into mainstream service provision; 4b: palliative care has been extensively integrated into mainstream service provision.

**SOURCE:** Prepared by the author with data from the World Health Organization (2013b), Pain and Policy Studies Group (2018), and Pastrana et al. (2012)

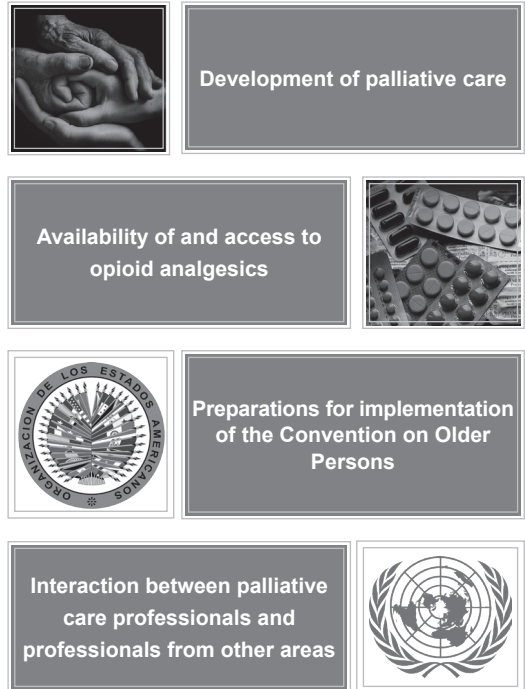


## Analytical Scope

The analysis focused on four dimensions (see figure 1).

These four dimensions allow for an analysis of normative characteristics and implementation, as well as the interactions among discussions on health, human rights, and drug policy.

**FIGURE 1**  
**Analytical scope**



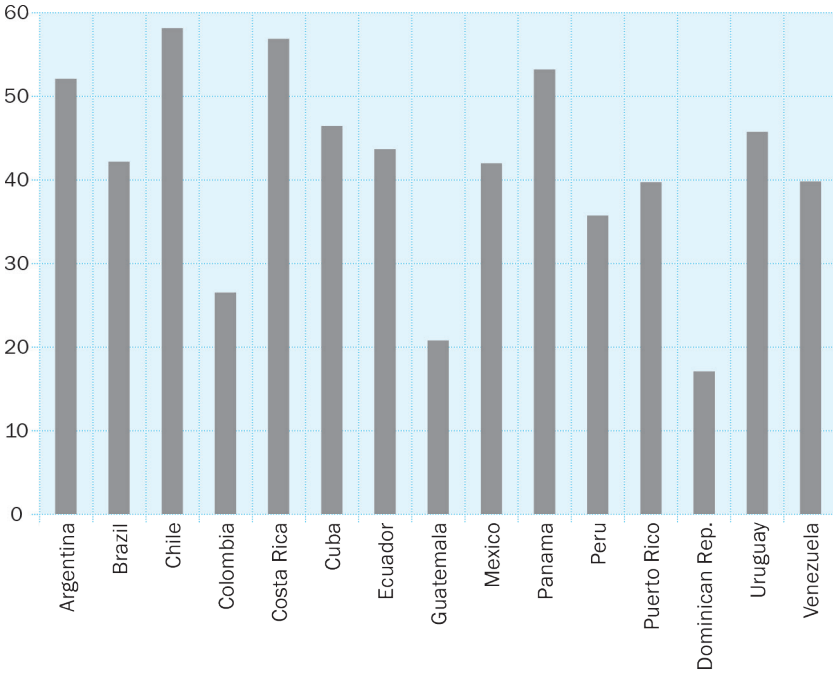
The research was complemented by interviews with contributors to the *Atlas of Palliative Care in Latin America* and with health professionals in each country. These actors were key for accessing information on the implementation of palliative care, understanding the relevant country's progress since the publication of the *Atlas*, and learning about advocacy activities concerning the Convention on Older Persons and debates on drug policy reform.<sup>2</sup>

### **Development of palliative care**

The most recent study on the global state of palliative care, entitled *Quality of Death Index*, analyzes eighty countries according to five dimensions.

<sup>2</sup> A list of interviewees is available in the annex.

**GRAPH 3**  
**Quality of Death Index (score out of 100)**



**SOURCE:** Economist Intelligence Unit (2015)

Except for Canada and the United States, the seventeen countries from the Americas reveal a significant lag in the availability of, quality of, and legal framework for palliative care. Chile holds the highest score (58.6 out of 100), while the Dominican Republic holds the lowest (17.2 out of 100) (Economist Intelligence Unit 2015). Graph 3 illustrates the scores of the fifteen Latin American countries.

A range of factors stand behind these differences in access to and the quality of palliative care. First are factors related to public policy, such as the existence of specific laws and programs on palliative care, the integration of palliative care into health systems, the existence of regulatory mechanisms, and resource allocations for palliative care. According to research conducted by the Worldwide Hospice Palliative Care Alliance in 2011—which classified countries into various levels of development according to their integration of palliative care into the health system (from none to advanced)—two of nineteen Latin American countries have emerging development of palliative care services, twelve have isolated palliative care provision, one has generalized provision, and three have

preliminary integration of these services. None of the region's countries have advanced integration according to the study's classification system (Pastrana et al. 2012, p. 24). According to the *Atlas of Palliative Care in Latin America*, at least eleven countries lack a law or national plan on palliative care.

Second are factors related to the education and training of personnel. Except for Chile, Cuba, and Uruguay, in most countries in the region, medical schools do not offer specific courses on palliative care. In countries such as Colombia, this material is part of the syllabus in just a few schools and is not part of the basic curriculum. On average, Latin American countries have fourteen palliative care instructors, a figure that ranges from zero (in Bolivia and Honduras) to forty-five (in Mexico). Brazil is the only country that publishes a scientific journal on palliative care.

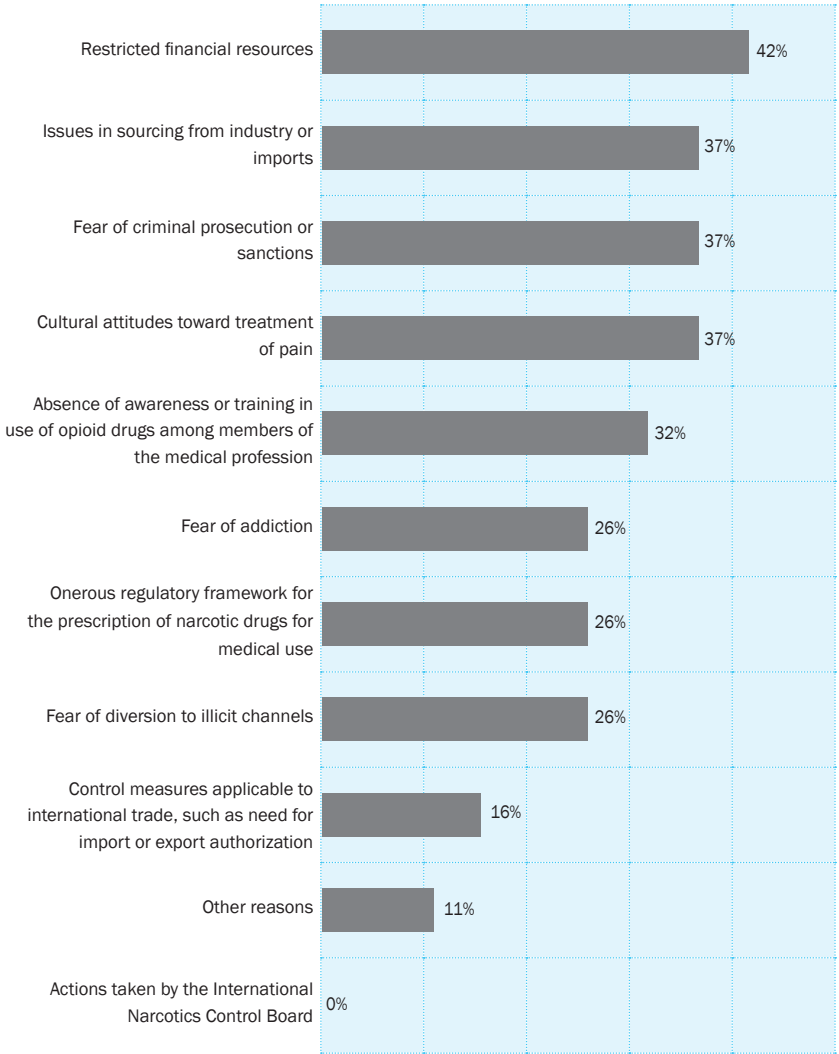
Factors relating to implementation include problems such as the absence of specialized infrastructure for palliative care. In Latin America, there are a total of 922 palliative care units in the entire region, which translates to 1.63 palliative care services/units/teams per 1,000,000 inhabitants. The number ranges from 16.06 (Costa Rica) to 0.24 (Honduras) facilities per 1,000,000 inhabitants. Forty-six percent of existing palliative care services in the region are concentrated in two countries (Argentina and Chile), attending to just 10% of the region's population. Other implementation problems relate to the lack of voice and the vulnerability of individuals who suffer from chronic or acute pain, the medical profession's focus on oncological pathologies, the marginalization of palliative care within the medical profession, and the perception that palliative care is, in the best of circumstances, "second-class health care," or in the worst, a failure of health care.

This dimension of the analysis presents the current palliative care situation in each country, paying special attention to national laws, programs, and implementation; professional training on the issue; oversight bodies; and the integration of palliative care into the national health system. To this end, it draws on information from the *Atlas of Palliative Care in Latin America* (2012), updating data where necessary. In addition, this aspect of the analysis explores the challenges and gaps in each country with regard to the effective integration of palliative care into mainstream health provision.

### Availability of and access to opioid analgesics

Opioids are an essential component of palliative treatment, as they constitute an effective and affordable tool for alleviating severe and chronic pain. Although they are on WHO’s list of essential medicines, their use in Latin America is relatively low. In 2013, average consumption in the region was 1.85 mg per capita, while in Canada and the United States it was

**GRAPH 4**  
**Barriers to the availability of opioids**



**SOURCE:** Prepared by the author based on Berterame et al. (2016, table 2)

88.73 mg per capita (Pain and Policy Studies Group, University of Wisconsin/WHO Collaborating Center 2015). Reports on consumption reveal that between 2011 and 2013, the regions of North America, Western Europe, and Oceania—home to a mere 15% of the world’s population—consumed 94.1% of the world’s opioid analgesics, while Latin America showed a modest increase in consumption levels (Berterame et al. 2016).

In 2015, a study was carried out that included a survey of competent national authorities and health professionals to evaluate the determinants of use, as well as barriers to accessing opioid analgesics (Berterame et al. 2016, p. 4).<sup>3</sup> For the Americas, nineteen of the region’s forty-four countries responded to the survey; their answers revealed that the main impediment is financial constraints, followed by legislative restrictions, cultural attitudes, and an absence of training on prescribing and administering these medicines. In addition, the study showed that higher impediments were associated with lower opioid use (p. 4) (graph 4).

Information on the global use of opioids is provided by the International Narcotics Control Board, which receives reports from competent national authorities estimating their country’s opioid need and consumption. This part of the analysis relies on data on per capita morphine consumption, as well as the country’s level of collaboration between prescribers and regulators. In addition, it presents an overview of the laws regulating opioids in each country, as well as the possible barriers standing in the way of access by doctors and patients. This information is complemented by interviews with physicians from each country.

### ***Preparations for implementation of the Convention on Older Persons***

The Convention on Older Persons, which will enter into force as soon as two countries have ratified it (OAS n.d.), outlines specific state obligations with regard to palliative care. Half of the countries selected for this study are signatories to the convention. To evaluate states’ progress in preparing for the implementation of this convention, this part of the analysis explores each country’s legal framework and relies on interviews with relevant actors regarding the existence or lack thereof of political and legal processes to ratify the convention. Regardless of a given country’s status as a signatory to the convention, this part analyzes national laws

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3 This study sent the survey to 214 national authorities.

and provisions on older persons. It pays special attention to the following articles of the convention, analyzing whether they have been incorporated into national law:

*Article 6. Right to life and dignity in old age*

Responsibility of state parties to ensure that public and private institutions offer older persons comprehensive health care, including palliative care.

*Article 11. Right to give free and informed consent on health matters*

Responsibility of state parties to prepare and enforce mechanisms that allow older persons to express their consent on health matters, including palliative care.

*Article 12. Right of older persons receiving long-term care*

Responsibility of state parties to adopt the necessary measures to ensure that older persons receiving long-term care also have access to palliative care that encompasses the patient, their environment, and their family.

*Article 19. Right to health*

Responsibility of state parties to implement intersectoral public health policies that do the following:

- Strengthen the capacities of health care workers.
- Promote and strengthen research and academic training in palliative care.
- Promote measures to ensure that palliative care is available to older persons and to support their families.
- Ensure that medicines included in WHO's essential medicines list, including medicines for palliative care, are available and accessible to older persons.

***Interaction between palliative care professionals and professionals from other areas***

The development of palliative care, particularly activism around its improvement and implementation, has benefitted from the participation of other sectors, such as health rights activists, activists for the elderly, and advocates of drug policy reform. In recent years, advocacy before the United Nations, particularly WHO<sup>4</sup> and the Office of the United Nations

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<sup>4</sup> World Health Organization, *Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course*, 67th World Health Assembly Resolution WHA67.19 (2014)..

High Commissioner for Human Rights,<sup>5</sup> has called on the need to improve access to palliative care, drawing particular attention to the urgent need to eliminate barriers to access that stem from the international drug control regime.

In this regard, the outcome document of the 2016 United Nations General Assembly Special Session on Drugs (UNGASS) dedicates a section to operational recommendations for countries, with the aim of ensuring the availability of controlled substances for medical and scientific purposes. The recommendations center on (i) examining and simplifying the processes for controlling substances for the relief of pain and suffering; (ii) strengthening national control systems in cooperation with the International Narcotics Control Board, the United Nations Office on Drugs and Crime, and WHO, among others; (iii) expediting the authorization process for the importation and exportation of controlled substances; (iv) specifically addressing the barriers that affect access to these substances at the national level; (v) training competent national authorities and health care professionals on access to and use of controlled substances; (vi) developing national supply management systems for controlled substances; and (vii) updating WHO's Model List of Essential Medicines.<sup>6</sup>

Given that the implementation of palliative care requires a multidisciplinary focus and that barriers to access are affected by factors outside the health sector, this part of the analysis examines the level of interaction that exists in each country between those working in palliative care, human rights, and drug policy. It relies on interviews, a review of active organizations in each country, and follow-up on the countries' positions during the 2016 UNGASS negotiation process. Such interaction occurs both at the level of civil society and at the level of government and decision making. This is because a focus on public policy advocacy around palliative care requires the development of additional strategies besides the design and implementation of laws, and also requires the establishment of dialogue with human rights activists and advocates for drug policy reform.

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5 United Nations, *Study on the Impact of the World Drug Problem on the Enjoyment of Human Rights: Report of the United Nations High Commissioner for Human Rights*, UN Doc. A/HRC/30/65 (2015), paras. 32, 33.

6 United Nations, *Our Joint Commitment to Effectively Addressing and Countering the World Drug Problem*, UN Doc. A/RES/S-30/1 (2016).

## **Limitations of the Analysis**

There are inherent analytical difficulties to exploring the provision of palliative care and the experiences of patients and their families. This study faced the following limitations:

The legal emphasis (e.g., standards governing opioids, standards regulating access to services, and standards guaranteeing the human rights of older persons) is limited in that it does not necessarily represent patients' realities. To the extent possible, the study explores whether these legal provisions are being implemented and applied; however, the diversity of experiences in the health sector makes it impossible to precisely comprehend the entire possible range of experiences in the implementation of these standards.

The doctors who were interviewed all live and work in the capitals of the countries under study, with one exception (Colombia). In this regard, the study presents the urban reality of palliative care and highlights, if known, the differentiated limitations that exist in peripheral and rural areas.

The interviews conducted with representatives of regulatory bodies, as well as representatives of the pharmaceutical industry, do not cover all of the countries analyzed, and, therefore, conclusions cannot be drawn from these narratives. The report uses this information to verify and contrast findings from previous studies on the topic.



### III. COUNTRY ANALYSES

#### **Argentina: In Search of the Universalization of Services**

Argentina is an upper-middle-income country and is party to all international drug control treaties (OAS n.d.). It is also a signatory to the Convention on Older Persons.

Argentina's health sector is characterized by a lack of coordination between the public, private, and social protection sectors, which is a key barrier to achieving universal coverage (Filguera and Hernández 2012, p. 8). Public social spending in the country has grown consistently since the 1980s, including during the severe economic crisis; this growth has included the health sector, whose spending has increased less dramatically but has hovered at around 20% of total spending in recent years (pp. 16–18).

In principle, Argentina's health system is universal, though effective access to good-quality health care services is unequal, depending on whether the care is provided by the public, private, or social protection sector. In addition, as a result of the decentralization of health care, low public investments, and a lack of oversight of health care entities throughout the country, the quality of care is highly variable, and patients must pay out of pocket for a high share of health expenses. Those with economic means tend to access private health care services, which are offered by for-profit entities (Filguera and Hernández 2012, pp. 35–36). The Ministry of Health's involvement is focused on public health initiatives, particularly care for vulnerable populations, with objectives such as the reduction of poverty and infant mortality (pp. 38–39).

According to WHO data for 2007, premature mortality in Argentina is due mainly to cardiovascular disease (47.3%), followed by cancer (37.3%), chronic respiratory diseases (9.1%), and diabetes (6.4%)

(World Health Organization 2012). Demographic changes will lead to a doubling of the population over the age of sixty in a few years. In 2010, 14.4% of Argentines fell within this age group; according to projections by ECLAC, this share will increase to 17.7% by 2030 and 24.1% by 2050 (2014, p. 36). In addition, Argentina has one of the highest rates of deaths caused by noncommunicable diseases (467.3 for every 100,000 inhabitants). These changes in the country's demographic and epidemiological profiles will require greater palliative care services.

### **Development of palliative care<sup>1</sup>**

Palliative care was introduced in 1982 through limited provision at private facilities and was subsequently integrated into the country's health regulatory framework in 2000. According to the scale developed by Wright et al. (2008), Argentina falls into category 4a, meaning that palliative care is in a preliminary phase of integration into mainstream service provision.

Argentina is home to many palliative care professionals, and in 2015 palliative care was recognized as a medical specialty. According to one of the doctors we interviewed, this development is a milestone for improving palliative care in the country, as it facilitates institutional recognition of such care, which in turn enables the appointing of palliative care practitioners within hospitals, improves practitioners' capacity to access and form professional associations, and facilitates practitioners' billing of health care facilities.<sup>2</sup>

With regard to clinical guidelines, progress has also been made with the recent publication of the *Manual on Palliative Care for Primary Health Care*. This manual was prepared with the assistance of two palliative care specialists, whose main emphasis is on care for cancer patients (Ministerio de Salud de la Nación 2015). The manual is directed toward primary care provision, reflecting an intention to integrate palliative care into this area of service. It is written in a didactic tone for professionals without previous knowledge of the area.<sup>3</sup>

Argentina's legal framework—namely Law 26742 on patients' rights—protects patients' right to receive comprehensive palliative care (Centro de Información y Documentación 2012). However, this law has

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1 Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

2 Interview with Dr. Nicolás Dawidowicz, January 2016.

3 *Ibid.*

been inadequate for ensuring availability, given that Argentina's administrative system grants each province the autonomy to define its own standards, and some provinces have not incorporated palliative care into their services. This, together with the country's fragmented health system and unequal quality of care, has resulted in an uneven development of palliative care throughout the national territory (Pastrana et al. 2012, p. 28).

In addition to the patients' rights law, Argentina has created palliative care commissions and programs within the Ministry of Health and the National Cancer Institute. However, these initiatives have not received budget allocations and lack monitoring and oversight mechanisms, making them ineffective in universalizing palliative care services. Although there are professionals trained in palliative care, as well as research and teaching activities on the issue, the integration of palliative care into mainstream service provision is still incipient and depends largely on the patient's ability to pay and on his or her province of residence.<sup>4</sup>

In general, Argentina's legal and programmatic provisions are aimed at ensuring palliative care for cancer patients, meaning that non-cancer patients in need of such care have difficulty accessing it. Although there are units for chronic pain management, there is no national program for chronic pain treatment facilities. Through such a model, care could be provided to all patients in need of pain relief.<sup>5</sup>

### **Availability of and access to opioid analgesics**

According to the *Atlas of Palliative Care in Latin America*, Argentina scores 4 out of 5 in terms of collaboration between regulatory agencies on opioid use and prescribers. Morphine consumption in Argentina is 7.30 mg per capita, among the highest in the Americas (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

As with access to palliative care, access to opioids is uneven, as it depends on the province, the physician's training, and availability of opioids in the location at hand. The range of standards results in barriers to access in some cases, as there is no availability of prescription books for physicians.

The following analysis, which describes the current situation and the main challenges, is based on interviews with a palliative care specialist

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4 *Ibid.*

5 *Ibid.*

(regarding the prescription phase) and a representative of the pharmaceutical industry (regarding the production and dispensation phase).

### *Prescriptions*

For the particular case of the doctor we interviewed, opioids are completely available at his hospital; he noted that, in general, patients in the federal capital do not have problems accessing opioids, as hospitals provide them free of charge.<sup>6</sup> The problem centers on prescriptions, for two main reasons: (i) legal difficulties and (ii) opiophobia, or fear of opioids.

According to the 1968 Narcotics Act,<sup>7</sup> the supply of these medicines to the public requires the prescribing physician to maintain a registry of prescriptions and send copies of each prescription to the relevant health care authority within eight business days. In addition, prescriptions may not exceed ten days of treatment. Doctors must go to a governmental building to purchase a prescription pad, which contains just twenty sheets of paper. Outside of Buenos Aires, these pads can be obtained in greater quantities of sheets and free of charge. In practice, many doctors triple the dosage of each prescription to be able to cover more treatment time than is provided for under the law.<sup>8</sup> For their part, pharmacies frequently prefer not to sell opioid analgesics in order to avoid cumbersome paperwork and certifications that must be obtained from health authorities.<sup>9</sup> In this regard, as in other countries, there is an urgent need for technological modernization in order to simplify regulatory authorities' tracking of opioids.

Besides legal difficulties, another barrier to access is opiophobia. Health care professionals and patients alike are uninformed about the effects of opioids. According to the doctor we interviewed, it is important that doctors be sufficiently educated on opioid analgesics so they can have productive conversations with their patients and inform them of the benefits and possible risks of this type of treatment.

### *Production and dispensation*

Since 2014, Argentina has been implementing a pilot program on the provision of opioids, operated jointly by the state-owned company Laboratorio Industrial Farmacéutico (LIF), the National Cancer Institute, and the

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6 Interview with Dr. Nicolás Dawidowicz, January 2016.

7 *Ley 17818: Estupefacientes* (1968), <http://www.anmat.gov.ar/webanmat/Legislacion/Medicamentos/ley17818.pdf>.

8 Interview with Dr. Nicolás Dawidowicz, January 2016.

9 *Ibid.*

Ministry of Health of the Province of Buenos Aires (MUNDO LIF – El Laboratorio Industrial Farmacéutico 2016). The program was designed collaboratively by state health authorities, drug regulatory agencies, palliative care specialists, and pharmaceutical specialists with the aim of creating pharmaceutical formulations that are practical for the management of severe and chronic pain.<sup>10</sup>

This pilot program has been implemented in nine public hospitals nationwide, where the LIF has delivered opioids that it has manufactured. Some hospitals have refused to accept the delivery of these medicines, possibly be due to pressure from the private pharmaceutical industry.<sup>11</sup> According to LIF’s director, the program, in addition to providing medicines to these hospitals, has shown that the public sector has the ability to produce high-quality medicines.

At the time of writing, the continuation of the pilot program and its extension to additional hospitals was uncertain. The need is very high, as palliative care coverage is expanding in primary care service provision. The experiences of some jurisdictions is leading to greater public demand for this type of care.<sup>12</sup>

### ***Preparations for implementation of the Convention on Older Persons***

Argentina’s national laws have partially incorporated the obligations outlined in the convention. The rights of older persons are not protected in any specific law on the issue. Since 2010, efforts have been underway to draft a law on comprehensive protection for older persons, though it has not been completed.

Article 11 of the convention, according to which the state should provide mechanisms and procedures for ensuring older persons’ right to provide free and informed consent on health matters, is incorporated into Law 26742, which guarantees patients’ autonomy over medical decisions, with a specific mention of palliative care. This law is not specifically geared toward the elderly, instead covering any patient in the country.

With regard to the convention’s protection of the rights of older persons receiving long-term care (art. 12) and the right to health (art. 19),

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**10** Interview with Guillermo Cleti, director of Laboratorio Industrial Farmacéutico, February 2016.

**11** *Ibid.*

**12** *Ibid.*

these are incorporated only to the extent of general guarantees for the right to health and a dignified life, as enshrined in Argentina's Constitution (Economic Commission for Latin America and the Caribbean 2011).

### ***Interaction between palliative care professionals and professionals from other areas***

Argentina is a signatory to the Convention on Older Persons, though it has not taken any legal steps at the national level to prepare for ratification.

In terms of its drug policy, Argentina has had a relatively low profile within the region. Although there have been national debates on alternatives to prohibition, the country is still governed by drug standards dating back to 1989 (Transnational Institute 2015a).

Palliative care professionals are active in their field, both at the level of professional networks and at the level of research.

### **Chile: Effective Progress based on the Legal Framework**

Chile is a middle-high-income country and is party to all international drug control treaties (OAS n.d.). It is also a signatory to the Convention on Older Persons.

The country, which boasts expansive health and education coverage, is a pioneer and leader in the region in terms of guarantees for economic and social rights. Although the 1980s were marked by structural reforms that reduced public health expenditures, in the decades following the dictatorship, the government focused on strengthening the network of public services and increasing public social spending (Robles Farías 2012). In particular, public spending on health has increased steadily, from 1.8% of the GDP in 1990 to 4.9% in 2009 (p. 12).

The health sector, governed by the Ministry of Health, consists public and private service provision. The public sector covers 73% of the population. However, there are important differences between the two sectors, both in terms of quality and in terms of the availability of services. For this reason, people with the means to do so generally obtain private health care, which is provided through contributory insurance schemes. Private health care is generally of better quality and offers a wider range of services (Robles Farías 2012, p. 27).

According to WHO data for 2007, premature mortality in Chile is due mainly to cancer (50.4%), followed by cardiovascular disease

(36.8%), chronic respiratory diseases (6.4%), and diabetes (6.3%) (World Health Organization 2012). The share of persons over the age of sixty is expected to double over the next forty years. In 2010, 13.5% of the population was over sixty; according to projections by ECLAC, this share will increase to 23.6% by 2030 and 33% by 2050 (2014, p. 36). Moreover, although mortality due to noncommunicable diseases is projected to decrease in the coming years, the prevalence of these diseases is expected to increase (Ministerio de Salud 2015, p. 3). These changes will manifest themselves in an increased demand for palliative care services.

### **Development of palliative care<sup>13</sup>**

Palliative care first emerged in Chile in 1990 through private providers and home care, becoming more extensive in 2004, when it was included in the country's legal framework. According to the scale developed by Wright et al. (2008), Chile falls into category 4a, meaning that palliative care is in a preliminary phase of integration into mainstream service provision.

One of the objectives of Chile's general health reform that began in 2000 was to adapt to epidemiological changes taking place in the country. This resulted in a law establishing the Explicit Health Guarantees System (GES, for its Spanish initials), passed in 2004, and a law establishing universal access to explicit health guarantees, passed in 2005, through which funding is allocated to the GES (Robles Farías 2012, pp. 27–28). These two laws provide the legal framework for palliative care in Chile, as they include explicit recognition of palliative care and require all public and private health providers to offer palliative care to patients in advanced stages of cancer.

Although this legal framework has implied the integration of palliative care into mainstream health care services, non-cancer patients—such as those living with HIV/AIDS and those with other chronic or terminal illnesses—continue to experience difficulties in accessing such care. If a patient with one of these illnesses visits a doctor, the doctor is not legally obligated to provide palliative care, and the management of pain with analgesics depends on whether the doctor is trained in prescribing opioids and whether these medicines are available in a pharmacy of a non-cancer facility.<sup>14</sup>

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**13** Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

**14** Interview with Dr. Marcela González, family practitioner with training in palliative medicine, palliative care unit at the Hospital Sotero del Rio and vice

Palliative care training is another aspect that requires improvement, since there are currently no postgraduate specialty training programs in palliative care. Some universities offer certificate programs or courses on the topic.

### **Availability of and access to opioid analgesics**

According to the *Atlas of Palliative Care in Latin America*, the country scores 4 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in Chile is 2.49 mg per capita (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

Access to opioids remains a problem for the management of terminal-ly ill patients in Chile, especially due to disparities between the public and private sectors and the neglect of non-oncological pathologies. In the public sector, which operates under the framework of the GES law, the availability of opioids is guaranteed in the pharmacies of public hospitals. Private pharmacies, on the other hand, do not always have an adequate supply.

Even though 70% of the population is covered by the public sector, those patients with economic means often purchase private care. In general, these patients enjoy better-quality care, but accessibility can be limited, as revealed in our interview with family practitioner Marcela González. The public sector offers better coverage for and access to palliative care than the private sector, given that such care is practically free and that public facilities have a vast availability of various types of opioids.

### **Preparations for implementation of the Convention on Older Persons**

In Chile, care for older persons is governed by the National Service for the Elderly (Servicio Nacional del Adulto Mayor and Ministerio de Desarrollo Social), a branch of the Ministry of Social Development. This institution is responsible for implementing protective laws for this population, which emphasize the prevention of violence and mistreatment of older persons.

Chile is a signatory to the Convention on Older Persons. However, not all of the state's obligations under the convention are incorporated into the domestic legal framework. In particular, there are no standards that operationalize article 11 of the convention, which requires the state

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president of Fundación de Cuidados Paliativos Gracias a la Vida, January 2016.



to provide mechanisms and procedures for ensuring older persons' right to provide free and informed consent on health matters.

The provisions of articles 12 and 19, regarding the rights of older persons who receive long-term care and the right to health, respectively, are not entirely integrated into Chile's domestic legal framework. With regard to palliative care, health care for the elderly emphasizes preventive actions and the strengthening of older persons' active participation in society, without mentioning a palliative focus (Ministerio de Salud n.d.).

### ***Interaction between palliative care professionals and professionals from other areas***

In terms of its drug policy, Chile has initiated national debates on drug policy reform and the need to incorporate a public health focus, particularly through the introduction of a bill seeking to decriminalize the cultivation of cannabis (Transnational Institute 2015b).

There is also political will to support the human rights of older persons, which is reflected by the fact that Chile was one of the countries to sign the convention during the OAS's forty-fifth General Assembly. Nevertheless, health care for the elderly continues to embrace a curative and rehabilitative focus, without focusing on the need to incorporate palliative care (Servicio Nacional del Adulto Mayor 2015).

### **Colombia: A Strong Professional Guild**

Colombia is a middle-income country and is party to all international drug control treaties (OAS n.d.). It has not signed the Convention on Older Persons.

Over the last twenty years, public social spending in Colombia has increased as a percentage of GDP. Nonetheless, health spending has been erratic: it increased considerably between 2006 and 2007, but then declined in 2008. In subsequent years, health spending has exhibited more stable behavior (Mina Rosero 2013, pp. 9–10).

Colombia has a comprehensive social security system, created by Law 100 of 1993 and complemented by Law 1751 of 2015, which govern the fundamental right to health. The implementation of the social security system is regulated by the Ministry of Health and Social Protection (MSPS, for its Spanish initials) and involves the participation of the private sector, which is the main actor in the administration of resources and the provision of services (Pan American Health Organization and

World Health Organization 2009). In the Colombian health system, citizens contribute resources through two regimes: the contributory regime (where citizens contribute in accordance with their income level) and the subsidized regime (where citizens access state-subsidized services free of charge). Through these two regimes, the country achieved 86% coverage of the population by 2008 (Mina Rosero 2013, p. 23). The health system has a package of services known as the Obligatory Health Plan, which includes a series of essential procedures and medicines that must be guaranteed by all health care providers. The Obligatory Health Plan was recently unified across the two regimes (contributory and subsidized) so that it contains the same services for both. In spite of this unification, however, inequalities persist, particularly in terms of quality (p. 21).

According to WHO data for 2007, premature mortality in Colombia is due mainly to cardiovascular disease (43.3%), followed by cancer (42.3%), chronic respiratory diseases (7.9%), and diabetes (6.6%) (Pan American Health Organization 2012). The country has a comprehensive policy for noncommunicable diseases,<sup>15</sup> outlined in its Ten-Year Public Health Plan for 2012–2021. However, according to WHO, the plan falls short in terms of failing to outline measurable results and failing to include components related to monitoring and evaluation. In addition, WHO highlights the lack of a multisectoral mechanism for policy coordination with regard to noncommunicable diseases.

The country's demographic profile will significantly transform in the coming years, with an expected tripling of the percentage of the population over the age of sixty. In 2010, 9.0% of the Colombian population was in this age group; according to projections by ECLAC, this share will increase to 18.6% by 2030 and 27.4% by 2050 (2015, p. 36). This, together with the incidence of noncommunicable diseases, will involve a transformation in the demand for health care services, particularly palliative care services.

### **Development of palliative care<sup>16</sup>**

Palliative care first emerged in Colombia in 1980 through private service provision and, in 1996, was recognized by the public health system.

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**15** Special attention is paid to noncommunicable diseases, since their treatment represents a large portion of the demand for palliative care services.

**16** Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

According to the scale developed by Wright et al. (2008), Colombia falls into category 4b, meaning that palliative care has been extensively integrated into mainstream service provision.

Although palliative care has been practiced in Colombia for many years—and the country is one of the pioneers in the region in terms of establishing pain management clinics—it was not until 2014 that palliative care as a health focus was integrated into national regulations beyond cancer control programs. That year, Congress passed Law 1733 of 2014, whose provisions aim to define the rights of patients with chronic, degenerative, or irreversible diseases with a significant life impact, including the right to palliative care, as well as to regulate the provision of these services by public and private health entities.<sup>17</sup>

This law set in motion processes for creating service guides and protocols, formalizing accreditations, and including palliative care education at all levels of training, among others. In particular, the MSPS is currently working on a process for the creation of a comprehensive care model that incorporates various methods of care.<sup>18</sup> In April 2016, the ministry issued a communiqué to health care providers, professionals, local authorities, and users with specific instructions on minimum requirements of care for all patients affected by chronic, terminal, or degenerative diseases.<sup>19</sup>

The main national program governing palliative care is the Ten-Year Public Health Plan, particularly with regard to the management of non-communicable diseases and strategies for addressing population ageing (Ministerio de Salud y Protección Social 2013, p. 141).

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**17** Congreso de Colombia, *Ley Consuelo Devis Saavedra, mediante la cual se regulan los servicios de cuidados paliativos para el manejo integral de pacientes con enfermedades terminales, crónicas, degenerativas e irreversibles en cualquier fase de la enfermedad de alto impacto en la calidad de vida* (2014), <http://wsp.presidencia.gov.co/Normativa/Leyes/Documents/LEY%201733%20DEL%2008%20DE%20SEPTIEMBRE%20DE%202014.pdf>.

**18** Presentation by Javier Carrera, official from the Ministry of Health and Social Protection, Congreso Nacional de Cuidados Paliativos, Bogotá, November 28, 2015.

**19** Ministerio de Salud y Protección Social, *Circular 0023: Instrucciones respecto de la garantía de los derechos de los pacientes que requieran cuidados paliativos en Colombia*, April 2016, <http://www.accpaliativos.com/#!Instrucciones-respecto-de-la-garantía-de-los-derechos-de-los-pacientes-que-requieran-cuidados-paliativos-en-Colombia/t8j8p/572372ce0cf26b6d68465c8f>.

The entity charged with implementation is the MSPS. However, as was witnessed during the National Congress of Palliative Care Residents, held in Bogotá in November 2015, specialized civil society associations are also playing an active role. They have developed guides and best practices, monitored the law's implementation, performed diagnostic studies on progress in palliative care in Colombia, and provided formal and informal education for medical professionals. In this sense, the government's actions have been reactive in the face of pressure from professional associations, which reflects the strength of health professionals working in palliative care, as well the willingness of the government to incorporate expert opinions into its processes.

### **Availability of and access to opioid analgesics**

According to the *Atlas of Palliative Care in Latin America*, Colombia scores 3.5 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in the country is 1.49 mg per capita (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

The National Narcotics Fund, an administrative unit under the MSPS, is in charge of the importation, dispensation, and distribution of opioid medications. This fund centralizes requests presented by department-level health secretariats from throughout the country. This institutional structure is underpinned by the MSPS's Resolution 1478 of 2006, which includes standards governing the control, manufacture, distribution, and oversight of controlled substances.<sup>20</sup> In recent years, progress has been made to improve the availability of and access to these medicines, particularly by extending the duration of medical prescriptions. However, several barriers to accessing such drugs persist: (i) regional differences within the country; (ii) inadequate training for health personnel; and (iii) restrictions on the transport of opioids, which leads to difficulties in their application for patients receiving home care.

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**20** See *Resolución 1478 de 2006, por la cual se expiden normas para el control, seguimiento y vigilancia de la importación, exportación, procesamiento, síntesis, fabricación, distribución, dispensación, compra, venta, destrucción y uso de sustancias sometidas a fiscalización, medicamentos o cualquier otro producto que las contengan y sobre aquellas que son monopolio del Estado*, <http://www.alcaldiabogota.gov.co/sisjur/normas/Norma1.jsp?i=20670>.

Article 8 of Law 1733 stipulates that the MSPS, the National Narcotics Fund, and health care providers (through pharmacies within the health system) must guarantee the availability and accessibility of opioids at all times. Nonetheless, our interview with María Mercedes Fajardo, a specialized doctor in pain management in the city of Cali, in southwestern Colombia, revealed that this law is not being fully complied with in various parts of the country. The importation of opioids is based on historical consumption from the prior period, but this estimate does not reflect actual needs, since many pharmacies throughout the country lack a sufficient stock of opioids. In other words, a vicious circle is at play: the existence of barriers leads to low estimates, which in turn leads to the distribution of insufficient quantities that are not recognized as such due to the aforementioned barriers.

In terms of training, there is a need for greater training for practitioners who treat terminally ill patients. The administration of opioids requires proper professional training, which allows both the patient and the physician to be certain that the best method of care is being utilized.

Lastly, the law contains specific provisions on the security of transportation of opioids. These measures mean that, many times, home care teams are unable to provide these medicines to their patients. This has direct repercussions on the quality of life of many terminally ill patients and effectively restricts access to pain medications.<sup>21</sup>

### ***Preparations for implementation of the Convention on Older Persons***

The convention's obligations for states are partially regulated in Colombia—on the one hand, in Law 1251 of 2008, which establishes rules to ensure the protection, promotion, and defense of older persons' rights,<sup>22</sup> and, on the other, in Law 1733 of 2014.

The Law on Older Persons (Law 1251 of 2008) includes provisions on the right to a dignified life, in accordance with the requirements of article 6 of the convention, which concerns the right to life and dignity in old age.

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**21** Information presented during a panel at the Congreso Nacional de Cuidados Paliativos, Bogotá, November 28, 2015.

**22** Congreso de Colombia, *Ley 1251 de 2008*, [http://www.icbf.gov.co/cargues/avance/docs/ley\\_1251\\_2008.htm](http://www.icbf.gov.co/cargues/avance/docs/ley_1251_2008.htm).

In terms of the convention's article 11, which concerns the right to give free and informed consent on health matters, Colombia also has regulations, although they do not explicitly cover the elderly. Resolution 1216 of 2015 of the MSPS contains general provisions on the right to die with dignity, particularly in its article 4, which includes the right to palliative care.<sup>23</sup> In 2016, the ministry issued Resolution 1051 regulating the right to make an advance health care directive.<sup>24</sup> This is a regulation of the state's obligation under article 11 of the convention, which calls for the creation of a specific mechanism that allows patients to indicate their will with regard to health care interventions, including palliative care. The MSPS's instructions for the care of patients entitled to palliative care, issued in April 2016, urge health care providers to apply this document in their practices.<sup>25</sup>

According to articles 12 and 19 of the Convention on Older Persons, which concern the rights of older persons receiving long-term care and the right to health, respectively, Colombia must adjust its policy frameworks toward an eventual ratification of the convention. The right to health is envisaged as part of the package of rights contained in Law 1251, and the state is obligated to provide health services that are appropriate for the elderly, particularly through the implementation of the National Policy on Ageing. But this policy does not mention palliative care, and its focus lies on strategies for active ageing and the protection of the older population (Ministerio de la Protección Social 2005).

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- 23** Ministerio de Salud y Protección Social, *Resolución 1216, por medio de la cual se da cumplimiento a la orden cuarta de la sentencia T-970 de 2014, de la Honorable Corte Constitucional en relación con las directrices para la organización y el funcionamiento de los Comités para hacer efectivo el derecho a morir con dignidad* (2015), [https://www.minsalud.gov.co/Normatividad\\_Nuevo/Resoluci%C3%B3n%201216%20de%202015.pdf](https://www.minsalud.gov.co/Normatividad_Nuevo/Resoluci%C3%B3n%201216%20de%202015.pdf).
- 24** Ministerio de Salud y Protección Social, *Resolución 1051 de 2016, por medio de la cual se reglamenta la Ley 1733 de 2014 en cuanto al derecho a suscribir el Documento de Voluntad Anticipada*, <http://ahc.org.co/documentos/prensa/RES-1051-16%20voluntad%20anticipada%20pacientes.pdf>.
- 25** Ministerio de Salud y Protección Social, *Circular 0023 de 2016: Instrucciones respecto de la garantía de los derechos de los pacientes que requieran cuidados paliativos en Colombia*, <http://www.accpaliativos.com/#!Instrucciones-respecto-de-la-garantía-de-los-derechos-de-los-pacientes-que-requieran-cuidados-paliativos-en-Colombia/t8j8p/572372ce0cf26b6d68465c8f>.

### ***Interaction between palliative care professionals and professionals from other areas***

In the international arena, Colombia's participation in forums related to palliative care and the rights of older persons has been minimal. On the other hand, with regard to drug policy reform, the country has undertaken a key role in debates in regional and global settings. Together with other countries in the Americas, Colombia has co-hosted a range of initiatives that highlight the need to incorporate a human rights perspective into drug policies. In particular, within the framework of the Office of the United Nations High Commissioner for Human Rights, Colombia spearheaded the preparation of a draft resolution urging the General Assembly to take into consideration the information issued by the Human Rights Council regarding the impact of drug policies on human rights.<sup>26</sup>

In addition, Colombia supported Uruguay, Argentina, Ecuador, Mexico, and Guatemala in the drafting of a resolution on drugs and human rights during the forty-fourth regular session of the OAS General Assembly (Transnational Institute 2014).

Nonetheless, Colombia's actions on the international stage have not been complemented by similar developments at the domestic level. Its drug policy dates back to 1986, although in 2015 important progress was made with the regulation, via presidential decree, of the use of cannabis for medicinal purposes (Transnational Institute 2015c).

### **Costa Rica: Accelerated and Successful Integration into Health Services**

Costa Rica is a middle-income country and is party to all international drug control treaties. It is also a signatory to the Convention on Older Persons.

The country's social security system is regulated by the Ministry of Health and implemented through the Costa Rican Social Security Fund (CCSS, for its Spanish initials), to which both employers and employees make contributions, with insurance through a noncontributory regime for those who live below the poverty line. Under this system, all beneficiaries, regardless of their contribution, are guaranteed a comprehensive

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<sup>26</sup> United Nations, *Contribution of the Human Rights Council to the Special Session of the General Assembly on the World Drug Problem of 2016*, UN Doc. A/HRC/28/L.22 (2015).

package of basic health services.<sup>27</sup> In 2014, the system covered 94% of the population, and the Pan American Health Organization has adopted it as a model for the Central American region (Seguro Social Costa Rica 2014).

According to WHO data for 2007, premature mortality in Costa Rica is due mainly to cancer (47.3%), followed by cardiovascular disease (39.3%), diabetes (7.2%), and chronic respiratory diseases (6.3%) (Pan American Health Organization 2012). Costa Rica's demographic profile implies future transformations in its ageing population. In 2010, 11.2% of the population was over the age of sixty; according to ECLAC, this proportion will increase slowly but steadily, at the same time that life expectancy will grow slightly. By 2030, the share of people over the age of sixty is expected to nearly double, reaching 20.8%, and by 2050 it is expected to reach 30.8%. According to these projections, Costa Rica will be home to one of the highest concentrations of older persons throughout the entire region (2015, p. 36). This will have a direct impact on the demand for palliative care.

### ***Development of palliative care***<sup>28</sup>

Despite the fact that palliative care first emerged in Costa Rica relatively recently—in 1990—it is one of the most advanced countries in the region in its provision. According to the scale developed by Wright et al. (2008), Costa Rica falls into category 4b, meaning that palliative care has been extensively integrated into mainstream service provision. This is a major strength of palliative care in the country, and it is reflected in practice with the creation of clinical guides and standards by the Ministry of Health, as well as the National Council for Palliative Care.

At the legislative level, palliative care does not have a dedicated law or national program. Its development and implementation has occurred under laws that are focused on particular issues (such as the law on benefits for caregivers) and under explicit references to palliative care in cancer and HIV/AIDS control strategies.

With the aim of unifying public policy on this issue, the National Council for Palliative Care was created in 2008 via presidential decree. Although a unifying law has yet to be created, the development of palliative care has benefitted from the work of the National Center for Pain

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**27** For a general description of Costa Rica's health system, see Castro (2012).

**28** Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).



Management and Palliative Care, a public entity within the CCSS. In addition, in 2015, the government announced that the center would receive a new facility with equipment and multidisciplinary staff for the care of patients with chronic or terminal illnesses (Caja Costarricense del Seguro Social 2015).

One of the most important legislative frameworks in Costa Rica is Law 7756, which concerns benefits for the caregivers of terminally ill patients. As physician Marco Ferrandino told us in an interview, this law is extremely important because it ensures income for caregivers, who do not need to be a family member of the patient.<sup>29</sup> From a broader social security perspective, this measure ensures that the person charged with caregiving is not left in a situation of vulnerability upon no longer receiving a salary, as happens in most countries. This law serves as a model for other countries in the region by guaranteeing protection not just for the patient but also for the network that sustains him or her.

Palliative care is offered by the public sector, private sector, hospices, multilevel services in community centers of the CCSS, and volunteer and civil society teams. By and large, palliative care services are provided in the public sector and are regulated by the CCSS. There are also private palliative care services offered by nongovernmental organizations.

Palliative care is recognized as a medical subspecialty and is offered as a postgraduate degree for physicians and as a master's degree. One shortcoming is that palliative care is not incorporated into undergraduate medical training in most universities and is mandatory in only one of the country's seven medical schools. There are two professional associations—the Costa Rican Federation for Palliative Care and the Costa Rican Association for Palliative Medicine and Pain Medicine—which interact with other associations at the regional and global levels; nevertheless, research on palliative care is weak (Pastrana et al. 2012, p. 113).

In conclusion, although Costa Rica enjoys an advanced level of development in palliative care, it needs to improve its implementation of existing laws and to strengthen training for health professionals at all levels. With regard to the legal framework, existing laws should be integrated into a unifying law on palliative care. To this end, the National Council for Palliative Care should play a key role in advising the Ministry of Health, as

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<sup>29</sup> Interview with Dr. Marco Ferrandino, palliative care specialist, December 2015.

well as at the legislative level. It is also important to involve the professionals who work with patients on a daily basis, in such a way that their experiences feed the development of a legal framework for palliative care. The legal framework should be accompanied by investments in infrastructure and technology to improve the quality of services.

With regard to training, it is important to ensure education in palliative care as part of medical training throughout the country and to strengthen training for all health professionals on the issue of opioid management.

### **Availability of and access to opioid analgesics**

According to the *Atlas of Palliative Care in Latin America*, Costa Rica scores 5 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in the country is 3.62 mg per capita, one of the highest in Latin America and, according to the specialist we interviewed, sufficient to meet demand (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

The CCSS, which is Costa Rica's only importer of opioids, has a system that distributes these medicines to all public pharmacies throughout the country, which are required by law to stock them.<sup>30</sup> In addition, the Ministry of Health has issued guidelines on the prescription of morphine. Opioids can be administered in hospitals and in hospice and home care settings, and their prescriptions are valid for thirty days.<sup>31</sup>

Nonetheless, there are areas for improvement in terms of opioid use for pain management. The specialist we interviewed pointed to two fundamental problems. The first of these is opiophobia, or fear of opioids, reflected in the fact that some physicians prefer not to prescribe them. The second is the lack of training to ensure the safer administration of opioid medicines. According to this physician, the problem in Costa Rica is not availability but rather "responsible accessibility." Opioids are widely available throughout the country, and the procedure for distributing, prescribing, and dispensing them is relatively simple. While in many ways this is an advantage for patients in need of pain relief, it can also imply a danger. Since any physician can prescribe these medicines, it is important to ensure that all health professionals receive specific training on the

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**30** Interview with Dr. Marco Ferrandino, palliative care specialist, December 2015.

**31** *Ibid.*

prescription and administration of opioids, with the aim of avoiding the medicines' misuse or abuse.<sup>32</sup>

### **Preparations for implementation of the Convention on Older Persons**

Costa Rica is a signatory to the Convention on Older Persons, which shows clear political will for the instrument's ratification.

In terms of its obligations under the convention, Costa Rica already has some of the required regulations. In 1999, the country passed the Comprehensive Law on Older Persons (Law 7935), regulated by presidential decree, which enshrines the rights of older persons—notable among its provisions are the right to an adequate standard of living and to social services, the right to physical and mental health, and the right to social security.<sup>33</sup> However, palliative care is not explicitly mentioned in this law; it is therefore important that the country's preparation for the convention's implementation ensure the inclusion of specific provisions on palliative care for older persons in order to guarantee respect for their human rights, particularly the rights outlined in articles 6 and 19 of the convention.

In terms of article 11 of the convention, which concerns older persons' right to provide free and informed consent on health matters, Costa Rica needs to issue regulations to protect this right. During 2015, and as of the time of writing, Congress was debating a bill on “the dignified death of terminally ill patients” that would regulate palliative sedation and passive euthanasia, as well as guarantee palliative care for people with terminal illnesses (*La Nación* 2015).

According to the specialist we interviewed, the discussion on palliative care has become excessively politicized and has failed to take into account the perspectives of health professionals and patients. He highlighted that, at the moment, physicians and caregivers accompany patients and families, informing them of the possible evolution of the patient's illness and its symptoms and explaining possible scenarios in which they might need to make a decision, in order to understand their opinions in this regard.<sup>34</sup>

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**32** *Ibid.*

**33** *Ley integral para la persona adulta mayor, Ley 7935 de 1999*, [https://www.oas.org/juridico/mla/sp/cri/sp\\_cri-int-text-per-adul-may.pdf](https://www.oas.org/juridico/mla/sp/cri/sp_cri-int-text-per-adul-may.pdf).

**34** Interview with Dr. Marco Ferrandino, palliative care specialist, December 2015.

In order to prepare for the convention's entry into force, Costa Rica should make progress on the legislative front in terms of establishing procedures and mechanisms for patients' free and informed consent regarding health matters, including palliative care.

### ***Interaction between palliative care professionals and professionals from other areas***

In terms of its drug policy, the country has maintained a low profile both in its domestic legislation and its foreign policy actions. Although Costa Rica has supported other pro-reform countries in the debate on drug policy reform, it has not become a spokesperson for any particular issue (Transnational Institute 2015d). In addition, it is worth pointing out that given Costa Rica's system on access to and availability of opioids, the controls imposed by the drug policy has not represented a barrier to accessing these medicines.<sup>35</sup>

According to the physician we interviewed, political debates on palliative care in Costa Rica are led by people who are far removed from the realities of working with terminally ill patients and their families. In this sense, there is a disconnect between political agendas and the practical priorities of palliative care. This is reflected not only with regard to palliative care and human rights but also with regard to drug policy reform (Transnational Institute 2015d).

In light of the above, strategic intersectoral alliances should be nurtured between physicians and activists on health rights and human rights. In light of the fact that Costa Rica has an advanced development of palliative care, that there is political will in certain sectors around the ratification of the Convention on Older Persons, and that civil society is aware of the needs of terminally ill patients, the time is ripe for advancing the cause of palliative care as a human right.

## **El Salvador: A Nascent and Centralized Development**

El Salvador is a lower-middle-income country and is party to all international drug control treaties (OAS n.d.). It has not signed the Convention on Older Persons.

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**35** In this sense, the most serious human rights impact of the drug policy is reflected in the disproportionality of sentences and in prison overcrowding. See Transnational Institute (2015d).

The social security system is regulated by the Salvadoran Social Security Institute (ISSS, for its Spanish initials), which governs the retirement system and health system. Changes to the country's economic situation, particularly in the 1990s as a result of the peace accords, have permitted increased public spending in social security, with an emphasis on expanding coverage to the entire population. Nonetheless, the social security system is extremely stratified, as it depends directly on contributors' capacity to pay. Many services are provided privately or through volunteers.<sup>36</sup> The governing body for the health sector is the Ministry of Health, which offers social security coverage to approximately 75% of the population through services arranged into three levels of care.

For 2013, according to the ISSS, just 25% of the country's population had health insurance (Instituto Salvadoreño de Seguro Social 2013). The Ministry of Health, through the Basic Integrated Health System (Sibasi), attends to this population. It is worth noting that there is no package of services and that Sibasi provides primary care.

Health services differ in quality depending on the provider. According to recent studies, social security—through the Ministry of Health—provides better services than the public health system (Martínez Franzoni 2013, p. 21). Private services are scarce and are reserved for those who can afford them. There are also agreements whereby private entities provide services to the public system, as is the case with palliative care.

According to WHO data for 2007, premature mortality in the country is due mainly to cancer (40.3%), followed by cardiovascular disease (37%), diabetes (13.3%), and chronic respiratory diseases (9.4%) (OAS 2012). El Salvador is also experiencing an important demographic transition. In 2010, 9.7% of the population was over the age of sixty; according to projections by ECLAC (2015), this proportion will increase slowly but importantly at the same time that life expectancy will grow slightly. The share of people over the age of sixty is estimated to increase to 14.7% by 2030 and to 23.4% by 2050. This, together with an increased incidence of noncommunicable diseases, will mean an increased demand for palliative care and provisions guaranteeing the rights of older persons.

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**36** For a general description of El Salvador's health system, see Martínez Franzoni (2013, pp. 21–24).

## **Development of palliative care**<sup>37</sup>

Palliative care has been offered in El Salvador since 2002; however, it is offered at just one facility, the Hospital de la Divina Providencia. According to the scale developed by Wright et al. (2008), El Salvador falls into category 3a, meaning that palliative care is patchy in scope.

The country has neither a national law nor a national program on palliative care, though currently it is making progress on a national cancer policy, being drafted by the Ministry of Health, which incorporates palliative care. This policy is currently under the process of ministerial review and authorization.<sup>38</sup> In addition, the country has advanced in terms of incorporating palliative care into plans on cancer prevention and control.

Under this framework, the country's service network has been expanded through the creation of six pain and palliative care clinics. Four of these clinics are in San Salvador and two are in key peripheral regions, Santa Ana and San Miguel. These clinics operate under regulations created by the Ministry of Health and represent an important achievement regarding the situation identified in the 2012 *Atlas of Palliative Care in Latin America*.<sup>39</sup> In collaboration with the ministry, professionals from the Hospital Divina Providencia have trained physicians who will work in these new pain clinics.

Moreover, since 2014, the Ministry of Health has been leading an intersectoral process for the creation of a national policy on the prevention and control of cancer, and has incorporated palliative care specialists into the discussions (Ministerio de Salud 2015). In 2015, it circulated a draft of the policy for review, which specifically included pain management and palliative care as components of the policy's main objective, in accordance with the right to health (Ministerio de Salud 2015). In addition, it is progressing in the approval of the National Palliative Care Program, presented to the Ministry of Health in August 2015.<sup>40</sup>

Given that the progress highlighted here has focused largely on cancer control, it is clear that the needs of non-cancer patients in El Salvador are being neglected. The eventual approval of the National Palliative Care

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**37** Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

**38** Interview with Dr. Marvin Colorado, palliative care specialist, Hospital Divina Providencia, January 2016.

**39** *Ibid.*

**40** *Ibid.*

Program would help integrate this care into a broader range of health services, with care for patients who require the management of pain caused by other illnesses.

In addition to modifying its legislative framework to incorporate palliative care into mainstream service provision, El Salvador should also recognize palliative care as a specialty of medicine and incorporate the topic into medical education for physicians and other professionals who work with the terminally ill. In 2012, there was hope that the Law on Medical Specialties would grant palliative care specialization to physicians with previous education or experience in the area—but to date, there are no regulations in this regard in the country.<sup>41</sup>

### **Availability of and access to opioid analgesics<sup>42</sup>**

The availability of and access to opioid medicines is a key problem in El Salvador.

According to the *Atlas of Palliative Care in Latin America*, El Salvador scores 2 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in the country is 0.32 mg per capita, one of the lowest in Latin America, which reveals that chronic and severe pain is not being adequately managed (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

Controlled medicines are regulated by the National Directorate of Medicines, which is charged with the importation, distribution, dispensation, and oversight of opioids. Under this framework, any physician certified by the Superior Council of Public Health may prescribe opioids; however, this does not mean that it is easy for patients to access these medicines.

To prescribe opioids, the physician must first visit the National Directorate of Medicines. This entity gives the physician a prescription pad containing fifty prescriptions, each with three copies (one for the physician, which must be delivered to the directorate; one for the patient; and one for the pharmacy). Once the physician has used the entire pad, he or

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<sup>41</sup> *Ibid.*

<sup>42</sup> Information on barriers to access was provided by Dr. Marvin Colorado and verified in consultations with competent authorities. See *Ley de Medicamentos* (2012), <http://www.diariooficial.gob.sv/diarios/do-2012/03-marzo/02-03-2012.pdf>.

she may request a new one after presenting copies of the fifty prescriptions from the previous pad.

Prescriptions are valid for one month; certain formulations of morphine (i.e., injections) have a maximum limit of three ampules. Most pharmacies in the country do not stock opioids, meaning that even if a physician prescribes these medicines, the patient may not be able to obtain them. It is worth clarifying that in the case of morphine ampules, the physician may request authorization from the National Directorate of Medicines to dispense larger quantities to the patient according to his or her needs; to date, this process is considered expeditious and does not create excessive delays in accessing the medicine.

According to the information we gathered, the following barriers can be identified with regard to access to medicines for pain relief in El Salvador<sup>43</sup>:

- Existing procedures disincentivize physicians because they require a significant investment of time and dedication. Although all physicians are able to prescribe opioids, many opt for non-opioid alternatives in order to avoid the paperwork required by the National Directorate of Medicines.
- The vast majority of pharmacies do not have an available supply of opioid analgesics. The few that do supply them are not open twenty-four hours a day or on weekends.
- The maximum limit for morphine injections is insufficient for pain management in some cases, as the injections last for just a week. In the event that a physician requests permission to prescribe a larger quantity, this process—although generally expeditious—can take several days or weeks, leaving the patient at risk.

Finally, there are shortcomings in the training of physicians—both during medical school and during specialized training—concerning opioid treatment. This factor, together with bureaucratic obstacles regarding prescriptions, contributes to many physicians' desire to prescribe non-controlled medicines, which are not as effective in the management of chronic pain but do not imply burdensome paperwork.

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**43** These barriers have already been documented in the 2012 *Atlas of Palliative Care in Latin America*. It is worth pointing out that no improvements have been reported to date.



## **Preparations for implementation of the Convention on Older Persons**

To date, El Salvador has not signed the convention. However, it did play an active role in the negotiations leading up to the convention's completion, particularly regarding the inclusion of provisions on palliative care. In February 2013, El Salvador hosted, in San Salvador, one of the sessions of the OAS's working group on the protection of the rights of older persons.<sup>44</sup> The planning for this session was led by the Secretariat of Social Inclusion. Despite the country's political will at the international level, however, this level of commitment is not reflected in the domestic legal framework.

With regard to the obligations laid out under the Convention on Older Persons, El Salvador has the Law on Comprehensive Care for Older Persons, passed in 2002. Although this law includes older persons' right to receive medical care with a focus on prevention and rehabilitation, it does not explicitly incorporate the right to health or the provision of palliative care.<sup>45</sup> In this regard, articles 6 and 19 of the convention, which obligate countries to guarantee the right to live with dignity and the right to health, respectively, need to be explicitly incorporated into El Salvador's regulatory framework.

In terms of article 11 of the convention, which requires states to provide mechanisms for ensuring older persons' right to provide free and informed consent on health matters, including palliative care, Agreement 186 of 2015, issued by El Salvador's Ministry of Health, provides a standard format for informed consent that is based on the Technical Guidance for the Promotion of the Human Right to Health. None of these instruments, however, explicitly mentions palliative care. The process for informed consent applies to "the evaluation and analysis pertaining to the specific need for therapeutic treatment, research, and procedures that

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**44** Permanent Council of the OAS, *Convocation of the Meeting of the Working Group on Protection of the Human Rights of Older Persons, to Be Held in San Salvador, El Salvador*, CP/RES. 1011 (1896/13) (2013).

**45** Legislative Assembly of El Salvador, *Ley de Atención Integral para la Persona Adulta Mayor* (2002), <http://www.asamblea.gob.sv/eparlamento/indice-legislativo/buscador-de-documentos-legislativos/ley-de-atencion-integral-para-la-persona-adulta-mayor>, chs. I, II, IV.

imply a risk.”<sup>46</sup> This therefore reflects a persistent health focus that privileges curative care over palliative care.

### ***Interaction between palliative care professionals and professionals from other fields***

El Salvador has participated in the drug policy debate in light of its status as a transit country for drug trafficking. While neighboring countries in the region, such as Guatemala, have declared themselves in favor of opening the doors to legalization, El Salvador has not been in favor of such initiatives (Transnational Institute 2015e).

Given that the development of palliative care is still in its infancy, that many barriers to accessing opioids persist, and that few initiatives question the existence of these barriers, there are currently no spaces for interaction between the human rights, health, and drug policy reform communities.

### **Guatemala: Low Morphine Consumption and a Pain Management Crisis**

Guatemala is a lower-middle-income country and is party to all international drug control treaties (OAS n.d.). It has not signed the Convention on Older Persons.

Guatemala’s health system is governed by the Ministry of Public Health and Social Assistance (MSPAS, for its Spanish initials). Although recent decades have seen increased public social spending in both relative and real terms, this has not been sufficient in the face of needs among the country’s rural and poor citizens. Critical economic inequalities exist as a result of the civil war (Martínez Franzoni 2013, p. 10). Insufficient public spending in health means that families often pay out of pocket for up to 65% of their health expenses (p. 20).

The country has a social security health system (through the Guatemalan Social Security Institute), a public health system, and private health care providers. Data on coverage is contradictory, as different sources present different figures. According to ECLAC, although 60% of the population has formal coverage, only 26% has effective coverage (Martínez Franzoni 2013, p. 20).

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46 Ministerio de Salud, *Acuerdo 186 de 2015*, [http://asp.salud.gob.sv/regulacion/pdf/acuerdos/acuerdo\\_186\\_formato\\_unico\\_consentimiento\\_informado.pdf](http://asp.salud.gob.sv/regulacion/pdf/acuerdos/acuerdo_186_formato_unico_consentimiento_informado.pdf).

According to WHO data for 2007, premature mortality in Guatemala is due mainly to cancer (36.5%), followed by cardiovascular disease (38.1%), diabetes (16.1%), and chronic respiratory disease (9.2%) (Pan American Health Organization 2012). Like other countries in the region, Guatemala is experiencing population ageing. Although the percentage of people over the age of sixty is relatively low, this proportion is expected to double in the coming decades. In 2010, 6.6% of Guatemalans were within this age group; this is expected to increase slightly, to 7.9%, by 2030 and to reach 15.4% by 2050 (Economic Commission for Latin America and the Caribbean 2015, p. 36). These changes, along with the fact that the last twenty-five years have also seen a 61% increase in noncommunicable diseases, will lead to an increased demand for palliative care (World Health Organization 2014).

### **Development of palliative care<sup>47</sup>**

Palliative care first emerged in 1998 through private home care services. According to the scale developed by Wright et al. (2008), the country falls into category 3a, meaning that palliative care is patchy in scope.

According to the *Atlas of Palliative Care in Latin America*, palliative care in Guatemala is scarce and limited to cancer-related treatment in third-level facilities in the capital. One specialist noted that in 2016 there had been no extension of palliative care services or operating units.<sup>48</sup>

Guatemala has neither a national law nor a national program on palliative care. There are palliative care leaders in the country who interact with decision-making spheres within the MSPAS. However, in recent years, the government has suffered critical changes due to corruption scandals, which has brought to light the system's shortcomings and deficiencies. In the midst of this political backdrop, it has not been possible to emphasize the need for regulations on palliative care, nor is the country expected to pass a law on this issue in the short or medium term.<sup>49</sup>

According to the *Atlas of Palliative Care in Latin America*, the most important achievement is expected in 2016, with the creation of the first master's degree in palliative care. This degree is aimed at any professional

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<sup>47</sup> Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

<sup>48</sup> Interview with Dr. Marisol Bustamante, palliative care unit at the Unidad de Oncología Pediátrica, January 2016.

<sup>49</sup> *Ibid.*

who works with terminally ill patients and seeks to strengthen the provision of palliative care in the country.

Lastly, there has been a growth in awareness of palliative care among Guatemalan citizens. In light of the low quality of health care in the country, the wealthy often travel abroad for medical treatments and have taken note of palliative care options elsewhere. Upon their return to Guatemala, they are demanding services that were previously unknown to the population.<sup>50</sup>

### **Availability of and access to opioid analgesics**

According to the *Atlas of Palliative Care in Latin America*, the country scores 2 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in the country is 0.04 mg per capita, the third lowest in the Americas (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

The Department for the Regulation and Control of Pharmaceuticals and Related Products, a branch of the MSPAS, is tasked with the importation, distribution, and oversight of controlled medicines.<sup>51</sup> Legal barriers to accessing opioids constitute one of the most difficult realities for patients with severe or chronic pain in Guatemala. In addition, there is a generalized fear among patients and physicians, caused by inaccurate information circulated in media outlets on the use of opioids.

Among patients, there is a lack of awareness of the medical use of opioids, given that these drugs are seen as medicines meant to end life and not as a tool for pain relief. There is also a fear of addiction to opioids. Among physicians, cumbersome administrative procedures serve as a disincentive to prescribing opioids. There is also fear among physicians of being investigated by regulatory authorities. Nonetheless, in a meeting with the MSPAS, the ministry clarified that in the last four years there were only two cases of physicians investigated for the improper prescription of opioid drugs.<sup>52</sup>

Low morphine consumption can also be explained by the cumbersome process required of patients in order to receive their medication.

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50 *Ibid.*

51 For a description of the process of accessing opioids in Guatemala, see Duarte (2014).

52 Interview with Dr. Marisol Bustamante, palliative care unit at the Unidad de Oncología Pediátrica, January 2016.

Each prescription must be authorized at the MSPAS, whose only office is in the capital. In some cases, pharmacies carry out this step for patients and their families, but in most cases they do not. The use of morphine is thus almost exclusively for people who live in the capital. Even if people who live in other areas go to the capital to complete this step, most pharmacies do not have an available supply of opioids.<sup>53</sup>

### ***Preparations for implementation of the Convention on Older Persons***

Guatemala lacks specific provisions on palliative care in general and in relation to older persons. Articles 6, 12 and 16 of the convention—which outline states’ obligations in terms of the right to life and dignity in old age, the right of older persons receiving long-term care, and the right to health, respectively—are covered generally in the Constitution. The Constitution stipulates that the state must provide comprehensive protection through the guarantee of certain economic and social rights (Economic Commission for Latin America and the Caribbean 2011). In addition, the Senior Citizens Protection Act, issued via Decree 80 of 1996, includes provisions on the rights of participation, to an adequate standard of living, and to health (p. 14).

The country lacks provisions, mechanisms, and procedures for guaranteeing the right to provide free and informed consent on health matters, an obligation laid out in article 11 of the convention.

In terms of a possible signature of the convention, the country is not taking concrete steps aimed at making progress. The political landscape in recent months has been less than favorable, and older persons and palliative care have not been a priority. In addition, a cultural component that privileges home care, ideally without physicians, is imposed on the management of symptoms and pain for older people.<sup>54</sup> With this in mind, and in the face of a possible signature, legislative efforts should be complemented with awareness-raising measures, as outlined in chapter V of the convention.

### ***Interactions between palliative care professionals and professionals from other areas***

The government of Guatemala has been one of the most active in the region in debates on drug policy reform. Together with neighboring countries, it

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53 *Ibid.*

54 *Ibid.*

has sponsored initiatives within the OAS and United Nations, where it has highlighted the negative consequences that the country has suffered as a result of being a drug corridor. In particular, the government supported Uruguay, Argentina, Ecuador, Mexico, and Colombia in the drafting of a resolution on drugs and human rights during the forty-fourth regular session of the OAS General Assembly (Transnational Institute 2014).

Nonetheless, Guatemala's actions on the international stage have not been complemented by similar developments at the domestic level. Congress has announced its intent to introduce legal reform on various occasions, though to date nothing has come to fruition; however, in 2013 Guatemala created the National Commission for Drug Policy Reform (Transnational Institute 2015f).

Professionals who work in palliative care generally have limited relationships with those working on drug policy reform. This is due in part to the limited number of palliative care physicians in the country, who must attend to a large number of patients and who must prioritize their professional practice over advocacy work. In the words of physician Mari-sol Bustamante, "the need is so great, and there are so few specialists, that there is no time for activism or other academic activities."<sup>55</sup>

## **Panama: Professionals and Volunteers as the Primary Drivers of Public Policy**

Panama is an upper-middle-income country and is party to all international drug control treaties (OAS n.d.). It has not signed the Convention on Older Persons.

The country's social security system has grown stronger in recent decades, partly due to increased public social spending (Rodríguez Mojica 2013, p. 13). In 1998, in an effort led by the Ministry of Health, the country began reforming this system in order to more efficiently integrate services (Ministerio de Salud 2013).

Social security policies have made progress in terms of guaranteeing social and economic rights (Rodríguez Mojica 2013, p. 29). With regard to health sector, the Social Insurance Fund (CSS, for its Spanish initials) has grown progressively since the 1980s, now covering 82% of the total population (Ministerio de Salud 2014). CSS is an autonomous body that provides health care services to the population belonging to the

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55 *Ibid.*

contributory regime, and it plays an important role in integrating palliative care services into mainstream health services.

According to WHO data for 2007, premature mortality in the country is due mainly to cardiovascular disease (41.2%), followed by cancer (41%), diabetes (10.2%), and chronic respiratory diseases (7.6%) (Pan American Health Organization 2012). Demographic projections show that over the next fifty years, the percentage of people over the age of sixty will double. In 2010, 9.8% of Panamanians fell within this age group. By 2030, this share will increase to 16.1%, and by 2050, it will reach 23% (Economic Commission for Latin America and the Caribbean 2015). In addition, in 2010, the rate of deaths caused by noncommunicable diseases increased by 33.6% (Ministerio de Salud 2013).

### ***Development of palliative care***<sup>56</sup>

Palliative care first emerged in Panama in 1992 with the creation of the pro-palliative care association Hospes. According to the scale developed by Wright et al. (2008), the country falls into category 4a, meaning that palliative care is in a preliminary phase of integration into mainstream service provision.

The Hospes association, the National Oncologic Institute, and individuals who work at these two entities have led the development of palliative care in the country. Hospes is an association that relies on donations and a team of volunteers dedicated to supporting palliative care in Panama.

In 2003, Panama passed Law 68 “regulating the rights and obligations of patients on matters of information and free, informed decisions.” This law is the first in the country to include language on palliative care; chapter 5 of the law, on the rights of terminally ill patients, obligates all hospitals to have palliative care units.<sup>57</sup>

In 2010, via Resolution 499, the National Palliative Care Program was created under the Ministry of Health. The program, which relies on Law 68 as precedent, aims to “contribute to the improved quality of life of terminally ill patients and their families.”<sup>58</sup> A national palliative care

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<sup>56</sup> Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

<sup>57</sup> Asamblea Legislativa de la República de Panamá, *Ley 68 de 2003*, <http://www.css.gob.pa/Ley%2068%20del%2020%20de%20noviembre%20de%202003.pdf>.

<sup>58</sup> Ministerio de Salud, *Resolución 499 de 2010*, [https://www.gacetaoficial.gob.pa/pdfTemp/26570/GacetaNo\\_26570\\_20100706.pdf](https://www.gacetaoficial.gob.pa/pdfTemp/26570/GacetaNo_26570_20100706.pdf), p. 8.

coordinator was assigned to ensure the resolution's implementation; this coordinator serves as the point of contact for other national-level entities and supervises the implementation of the National Palliative Care Program throughout the country.

These two legal frameworks, which were driven by health professionals seeking to incorporate palliative care into all health services throughout the country, reflect these professionals' advocacy capacity and leadership to shape policy. In particular, within the CSS, the implementation of Resolution 499 has resulted in the widening of services to include more operational teams, as well as training for pharmacy professionals, nurses, and social workers. As part of this effort, palliative care is being incorporated into all health service units, thus making headway in non-cancer areas, such as nephrology, infectology, neurology, geriatrics, and pediatrics.<sup>59</sup>

In addition, palliative care specialists have collaborated to develop a guide for end-of-life care that seeks to advise physicians, palliative care teams, primary care teams, and home care teams on the treatment and care of prevalent diseases. This guide on clinical management in the CSS is not an official one, and therefore its use is merely recommended—and, consequently, it reflects the fact that, in Panama, palliative care specialists are capable of taking initiative to improve the quality of care offered to terminally ill patients.

In terms of professional development, Panama is working on making palliative care a formal medical specialty, as well as establishing professional accreditation for physicians who have worked in this area for many years. Although palliative care professionals have been working on this issue for more than fifteen years, for several years no professional association had been created, which is a requisite under law to be able to present an application for accreditation before the Medical College of the Ministry of Health. It was not until November 2012 that the Panamanian Palliative Care Association was created, and in November 2014, it achieved legal status. The first objective in its work plan is to achieve recognition of palliative care as a medical specialty in Panama, a process that will likely take one more year. In addition, it will apply before the Medical College

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59 Interview with Dr. Nisla Camaño, national coordinator of palliative care and of the Programa Nacional de Cáncer, Caja de Seguro Social de Panamá, January 2016.



to create an accreditation for professionals who have worked in palliative care for more than five years. These efforts will remedy one of the key obstacles currently standing in the way of palliative care development in Panama.<sup>60</sup>

Formal recognition of palliative care as a specialty will facilitate the expansion of palliative care in all subspecialties, and it will raise awareness among medical professionals who still do not view this area of medicine as necessary or important.<sup>61</sup> In this regard, the work of the Panamanian Palliative Care Association will be critical for channeling efforts and overcoming resistance among certain physicians to incorporating this dimension into their medical practices.

Lastly, there is a need in Panama to expand palliative care's use for non-oncological illnesses. According to the specialist we interviewed, although the most prevalent noncommunicable disease in Panama is chronic kidney disease, the implementation of palliative care—from specialists to operative units—is still concentrated in cancer care.

### ***Availability of and access to opioid analgesics***

According to the *Atlas of Palliative Care in Latin America*, Panama scores 3.5 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in the country is 0.22 mg per capita, one of the lowest in Latin America, which reveals that chronic and severe pain is not being adequately managed (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

Problems in the availability of and access to medicines for the treatment of pain are attributed to fear and the lack of trained medical personnel, along with an outdated and restrictive legal framework. Although Panama updated its opioids law in 2009 (which had dated back to 1954) by extending the validity period of prescriptions (Pastrana et al. 2012, p. 257), the country's low morphine consumption suggests that physicians are not prescribing sufficient opioid medicines to satisfy the needs of terminally ill patients. All of this results in a vicious circle: consumption is low, which means that estimates used to calculate future importation requests are equally low, which in turn results in low quantities of opioids available throughout the country. At the end of 2015, following a meeting

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60 *Ibid.*

61 *Ibid.*

of the logistics department of the National Directorate of Pharmacies and Drugs, the directorate determined that relying on historical consumption levels to project future importations was not the best method; thus, for the subsequent year, the quantity estimated for importation was calculated according to need. This means that 2016 will be the first year in which the country enjoys a greater availability of opioids. This, together with greater awareness among medical professionals, should result in increased consumption of opioid analgesics for the treatment of pain.<sup>62</sup>

With the aim of demystifying opioids and alleviating the fears of many health professionals concerning the dispensation and administration of these drugs, the CSS has trained 325 people in various regions throughout the country. These workshops, which last for two days, embrace a practical-theoretical focus and are aimed at professionals who have regular contact with terminally ill patients, including nurses, pharmacists, and physicians. Moreover, the CSS conducted trainings in 76 of its pharmacies on current regulations in the country, given reports that these pharmacies had been denying medicines to some patients—even those with prescriptions—due to their lack of awareness of the 2009 reform to the opioid law.<sup>63</sup>

With regard to the legal framework, the link between health professionals and the Pharmaceuticals Committee of the CSS is being maintained with the aim of modifying prescription and distribution processes, ensuring the availability of opioids in all primary care clinics, and better regulating the medical use of controlled medicines (Asamblea Nacional de Panamá 2015). Although a policy has been approved, it has yet to be published in the *Gaceta Oficial*, which will then be followed by a regulatory process.<sup>64</sup>

### ***Preparations for implementation of the Convention on Older Persons***

Panama has already incorporated many of the convention's obligations into its national law. Palliative care, which is regulated by ministerial resolution, is integrated into health services, thus complying with the requirements of articles 12 and 19 of the convention, which concern the rights

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62 Interview with Dr. Nisla Camaño, national coordinator of palliative care and of the Programa Nacional de Cáncer, Caja de Seguro Social de Panamá, January 2016.

63 *Ibid.*

64 *Ibid.*

of older persons receiving long-term care and the right to health, respectively. On the other hand, Law 68 of 2003 regulates the legal provisions regarding the right to give free and informed consent on health matters, which is enshrined in article 11 of the convention.

Moreover, in 2014, the National Council for the Elderly was reactivated, in an effort led by the social development sector with participation from the health, housing, education, and labor sectors (Ministerio de Desarrollo Social 2014). In terms of the convention's eventual ratification, this council will be critical for articulating the main areas where older persons' right to palliative care should be integrated.

### ***Interactions between palliative care professionals and professionals from other areas***

Panama played an active role in Geneva when WHO was developing Resolution 67.19 on palliative care. Public officials from the National Palliative Care Program took the initiative of promoting the cause before WHO, highlighting their experiences in Panama and the need to put the issue on the international stage (Ehospice 2014).

In terms of drug policy, Panama has not played a prominent role in current debates in the Americas. On several occasions, Panama has opposed the initiatives of neighboring countries, such as Guatemala, concerning the possible decriminalization or legalization of the consumption of psychoactive substances (Transnational Institute 2015f). The government's reticence to envision alternatives other than prohibition could help explain the generalized fear in Panama regarding opioids, including for medical use.

### **Uruguay: Between Access to Opioids and Fragmented Services**

Uruguay is an upper-middle-income country and is party to all international drug control treaties (OAS n.d.). It is also a signatory to the Convention on Older Persons.

Uruguay is one of the region's most advanced countries in terms of human development, which is centered on the pillars of public social spending on education, health, social security, and housing (Repetto and Potenza dal Masetto 2012, p. 7). Although social spending on health has been erratic over the past few decades, it has seen a consistent increase in recent years (p. 11).

The health system, which was developed simultaneously in the public and private sectors throughout the twentieth century, is governed by the Ministry of Public Health in terms of public policy aspects. The Public Health Services Administration is responsible for the provision of public health services, while collective health care institutions deliver care in the private sector. The two systems offer the same services and access to health care, but with differences in quality: the private sector has better infrastructure and staff, and shorter waiting periods (Repetto and Potenza dal Masetto 2012, pp. 19–20). In Uruguay, 100% of the population is insured in one of these two systems (p. 21).

According to WHO data for 2007, premature mortality in the country is due mainly to cancer (53.2%), followed by cardiovascular disease (36.2%), chronic respiratory diseases (7.7%), and diabetes (2.9%) (Pan American Health Organization 2012). Demographic changes in Uruguay will imply a number of corresponding changes, even if we take into account that the country already has a significant population of people over the age of sixty. In 2010, 18.5% of the population was over sixty, representing the highest such percentage in Latin America. According to projections by ECLAC (2015), this proportion will increase to 22.3% by 2030 and 27.8% by 2050. This, together with the incidence of noncommunicable diseases, will mean an increased demand for palliative care.

### **Development of palliative care<sup>65</sup>**

Palliative care first emerged in Uruguay in 1985 through private providers. Subsequently, in the mid-1990s, palliative care was incorporated into medical training. According to the scale developed by Wright et al. (2008), the country falls into category 3a, meaning that palliative care is patchy in scope. This is reflected by the fact that, in 2011, according to a survey conducted by the Ministry of Public Health, 82% of the population in need of palliative care had not received it (*El País* 2014).

Uruguay's legal framework for palliative care is based on Law 18211 of 2007 establishing the National Integrated Health System, which integrates palliative care into the model of comprehensive health care.<sup>66</sup> To

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<sup>65</sup> Unless otherwise noted, the source for this section is the *Atlas of Palliative Care in Latin America* (Pastrana et al. 2012).

<sup>66</sup> Asamblea General de Uruguay, *Ley 18.211 de 2007: Sistema Nacional Integrado de Salud*, <http://www.parlamento.gub.uy/leyes/AccesoTextoLey.asp?Ley=18211&Anchor>, art. 4.

date, there are no specific laws on palliative care; the provision of such care is guided by the National Palliative Care Plan, issued by the Ministry of Public Health in 2013 (Ministerio de Salud Pública 2013a).

The most important progress in palliative care has occurred under the framework of this plan. The Ministry of Public Health has published a guide on best practices that encourages the provision of palliative care according to relevant regulations and with an emphasis on patients' human rights (Ministerio de Salud Pública 2013b). These represent steps toward the effective integration of palliative care into mainstream health care.

Both the design and the implementation of the National Palliative Care Plan, however, have significant shortcomings. The plan's provisions are voluntary, and health care providers do not have sufficient incentives to implement them. In addition, the plan's minimum training requirements for personnel who provide palliative care are inadequate, and the plan does not control the level of training for palliative care teams, which jeopardizes the quality of such care.<sup>67</sup>

Furthermore, there is a lack of in-depth palliative care training at all levels. Although the University of the Republic of Uruguay offers a specialist diploma in palliative care, the university's reach is not wide enough to cover the country's needs. Finally, palliative care training has not been incorporated into general undergraduate medical education.

### **Availability of and access to opioid analgesics**

According to the *Atlas of Palliative Care in Latin America*, Uruguay scores 3.7 out of 5 in terms of collaboration between regulatory authorities on opioid use and prescribers. Morphine consumption in the country is 4.32 mg per capita (Pain and Policy Studies Group, University of Wisconsin, WHO Collaborating Center 2015).

Law 14294 of 1974 establishes a state monopoly on the importation and exportation of psychoactive substances, as well as requirements for their dispensation for medical use and the obligation of pharmacies and other dispensers to ensure the traceability of medicines that are manufactured and prescribed.<sup>68</sup> According to the physician we interviewed, the manner in which Uruguay has implemented the international drug

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<sup>67</sup> Interview with Dr. Eduardo García Yanneo, clinical oncologist and palliative care specialist, April 2016.

<sup>68</sup> *Decreto Ley 17294 de 1974*, [http://www.infodrogas.gub.uy/html/marco\\_legal/documentos/02-DecretoLey14294.pdf](http://www.infodrogas.gub.uy/html/marco_legal/documentos/02-DecretoLey14294.pdf).

control regime—as far as opioid medicines are concerned—is well formulated, and its relationship with oversight bodies is fluid.

Opioid consumption began to decline at the beginning of the 2000s and has remained at low levels, which is a cause for concern because it suggests that a significant number of physicians are not prescribing opioids. Taking into account the implementation of the National Palliative Care Plan, the physician we interviewed concluded that, today, twice as many patients are being cared for but with the same quantity of opioids.<sup>69</sup>

The availability of and access to opioid medicines in Uruguay is mixed. While all necessary formulations are widely available and prescribed in the capital, other parts of the country—which are home to half of Uruguay’s population—have low prescription rates for formulations such as transdermal fentanyl and oxycodone, which suggests that a significant portion of the country’s population is being denied access to this kind of opioid medicine. In addition, while the guide on best practices includes some of these formulations, this recommendation is not obligatory for health care institutions; many institutions thus decide to remove these costly analgesics from their stocks, even though they are valid and necessary for pain management.<sup>70</sup>

The aforementioned problems regarding availability and access are based on a lack of trained health professionals, which leads to low prescription levels. This, together with a national policy that aims to increase coverage without increasing opioid consumption, leads to low consumption levels. In conclusion, the difficulties of availability and access stem from design-related shortcomings in palliative care provision and the distribution of medicines, but not to restrictions related to drug control.<sup>71</sup>

### ***Preparations for implementation of the Convention on Older Persons***

Uruguay’s laws partially integrate the obligations laid out in the convention. Care for the elderly is implemented by the National Institute for Older Persons, an arm of the Ministry of Social Development created by

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69 Interview with Dr. Eduardo García Yanneo, clinical oncologist and palliative care specialist, April 2016.

70 *Ibid.*

71 *Ibid.*

Law 18617 of 2009. This law requires collaboration with the ministry for the purposes of comprehensive health care for the elderly.<sup>72</sup>

Nonetheless, the current legal framework does not incorporate the obligations laid out in articles 6 and 19 of the convention, which concern the right to life and dignity in old age and the right to health, respectively. In general, none of Uruguay's legal provisions on older persons makes reference to palliative care, instead focusing on strategies for the promotion of healthy ageing.<sup>73</sup>

Article 12 of the convention, which concerns the rights of older persons receiving long-term care, is incorporated into domestic law via Law 17066 regulating long-term care, although the law does not specifically mention palliative care.<sup>74</sup>

Meanwhile, Law 18473 of 2009 regulates the convention's provisions on the right to give free and informed consent on health matters (art. 11 of the convention).<sup>75</sup> Although this law is not specific to the elderly, it provides mechanisms and procedures for ensuring older persons' ability to express their will regarding health matters. However, the law does not mention palliative care.

### ***Interactions between palliative care professionals and professionals from other areas***

Uruguay is among the most proactive countries in terms of drug policy; in 2013, it became the first country in the world to legalize all uses of cannabis (Transnational Institute 2015g). During this policy process, activists for drug reform turned to palliative care professionals in search of scientific evidence to justify the medical use of marijuana.

The softening of drug controls at the domestic level has been accompanied by a discourse at the regional and international level that calls

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72 Asamblea General de Uruguay, *Ley 18.617 de 2009: Instituto Nacional del Adulto Mayor*, <http://www.parlamento.gub.uy/leyes/AccesoTextoLey.asp?Ley=18617&Anchor=>.

73 Asamblea General de Uruguay, *Ley 17.796 de 2004: Promoción integral de los adultos mayores*, <http://www.parlamento.gub.uy/leyes/AccesoTextoLey.asp?Ley=17796&Anchor=>.

74 Asamblea General de Uruguay, *Ley 17.066 de 1998: Hogares de ancianos*, <http://www.parlamento.gub.uy/leyes/AccesoTextoLey.asp?Ley=17066&Anchor=>.

75 Asamblea General de Uruguay, *Ley 18.473 de 2009: Voluntad Anticipada*, <http://www.parlamento.gub.uy/leyes/AccesoTextoLey.asp?Ley=18473&Anchor=>.

attention to the need to explore alternatives and prioritize public health and human rights in matters relating to drugs. In this regard, Uruguay has sponsored resolutions, events, and reports in various international forums.



#### IV. CONCLUSIONS AND RECOMMENDATIONS

Palliative care as a focus of health and practice requires addressing illness from a different lens—one that embraces an interdisciplinary perspective and a new way of thinking about the role of medicine. In terms of public policy, the implementation of palliative care requires states to give due consideration to the human rights of people suffering from chronic or severe illnesses, as well as to adopt a drug control policy that places due importance on medical uses of controlled substances. In general, a palliative care focus improves the quality of life for patients and their families alike.

The countries analyzed here are diverse in their levels of palliative care development and their experiences. However, they all face similar problems given that the medical specialty of palliative care is a recent development and both its professional practice and its ability to influence public policy are still nascent.

These countries' experiences offer important lessons that can guide professional, regulatory, and legal practices in becoming more conducive to improving the quality of life and death among those suffering from avoidable pain.

Below are several conclusions and recommendations.

- **Abandon the curative fixation of medicine and public health.** The difficulties in developing palliative care and integrating it into mainstream service provision offer evidence of the obsession on healing and curing, as well as the curative emphasis of modern medicine. This can be seen in plans regarding care for the elderly, which in most countries emphasize healthy habits and active ageing, as in the cases of Chile and Uruguay. While these are important aspects of any person's well-being, part of the human reality also includes illness and death. Medical practice and public policies should turn

their view toward these processes of life and death and refrain from offering—much less forcing—patients to endure unnecessary treatments, especially when the most crucial consideration is to alleviate pain and suffering.

- **Close the gap derived from bias toward cancer patients.** In most countries, the implementation of palliative care is based on cancer control and care plans, as seen in the cases of Argentina and Chile. As a result of this tendency, there is a bias in palliative care toward cancer-related settings and, therefore, a disregard for patients with other pathologies that equally require palliative care. The implementation of the Convention on Older Persons offers an opportunity to leverage palliative care efforts toward other types of illnesses that require the same care in terms of managing symptoms and relieving pain.
- **Ensure that laws and policies are accompanied by budget allocations.** Progress in palliative care development is not necessarily the result of legal frameworks or public policy. Countries that demonstrate positive results have divergent experiences. In the case of Costa Rica, good-quality services with a high level of integration are offered to patients, despite the lack of specific laws or national programs. In the case of Chile, the GES law was the milestone that improved palliative care provision. These differences show that the legal framework is not the only ingredient for developing better medical practices for terminally ill patients and that the role of leaders and professionals who are dedicated to the cause is equally important. Furthermore, the normative assimilation of palliative care is not always a sign of development and access. Here, the case of Argentina is illustrative to the extent that there are many palliative care professionals and a series of laws and regulations at the national level, but the lack of budget allocations and inequalities in the general health system result in highly unequal access to palliative care. The process followed by Chile, which combines legal norms with specific budget allocations, has led to positive results for patients and their families. However, this does not mean that laws and standards with regard to palliative care are irrelevant. Even without budget allocations, these kinds of rules introduce a language within the community of health professionals, patients, educators, and policymakers that can become a useful symbolic tool to guarantee access to palliative care.

- **Shape excellent leaders.** Best practices and advances in palliative care are largely the result of the efforts of leaders who shape public policy to conform to demographic and epidemiological changes in their countries. The cases of Panama, Guatemala, and Colombia are good examples. Professionals in these countries have taken it upon themselves to address the shortcomings of their governments, generate initiatives to train professionals, develop and disseminate clinical guidelines, and pressure the government to adopt necessary institutional reforms. These individuals, who accompany patients and their families during the final stages of life, are critical for advancing the cause of palliative care.
- **Use education as a tool to overcome opiophobia.** Reluctance to prescribe opioids stems, in most cases, from fear of addiction and possible health complications and, to a lesser extent, from fear of legal sanctions. This reflects an enormous vacuum in the training of health professionals with regard to the safe administration of opioid medicines. Beyond simplifying current legal standards for the control of these substances, overcoming opiophobia requires public policy interventions that promote greater understanding of the utility of such medicines. The development of palliative care in the Americas should prioritize education for physicians, nurses, pharmacists, and other health professionals so that these practitioners can be certain of their ability to prescribe and administer these medicines, as well as to inform their patients of the benefits and possible risks.
- **Foster collaboration among palliative care specialists and the human rights community.** A human rights approach reinforces the need to integrate palliative care into health systems and to comply with obligations under the Convention on Older Persons. The convention's eventual entry into force, along with its ratification by additional countries, will open the door for demanding rights protections via the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights. In such scenarios, states will be held accountable for their progress in guaranteeing older persons' right to palliative care. This historical conjuncture is conducive to the strengthening of collaboration between palliative care professionals and human rights organizations, in which each group contributes its expertise and specific knowledge.

- **Incorporate a public health focus into drug policy.** The discourses on drug policy reform and palliative care are highly disjointed. Even in countries such as Uruguay, Chile, and Colombia—which have been progressive and active in the debate on drugs, emphasizing the need to incorporate human rights and public health perspectives—there is silence regarding the barriers imposed by drug policies on the legitimate use of certain medicines, such as for pain relief. The final document from UNGASS in 2016 is useful for governments and activists in both sectors in terms of simplifying repressive measures and undertaking the necessary reforms to domestic drug policies in the run-up to the next Special Assembly in 2019. Furthermore, the 2016 UNGASS discussions reflected a consensus around the need for drug policies—regardless of the position taken by each country—to safeguard the convention’s objectives of ensuring the availability of controlled drugs for medical purposes.

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## ANNEX

### List of people interviewed

Telephone interviews were conducted between December 2015 and April 2016.<sup>1</sup>

The interview format adhered to a semi-open general questionnaire, with semi-structured questions on each of the dimensions of analysis.

- **Argentina:** Dr. Nicolás Dawidowicz, palliative care specialist, coordinator of Hospital Público Municipal, January 2016.
- **Chile:** Dr. Marcela González,\* palliative care specialist and chief of the Palliative Care Unit at Hospital Sotero del Rio, January 2016.
- **Colombia:** Dr. María Mercedes Fajardo, anesthesiologist with expertise in pain and palliative care, coordinator of Programa Hospital sin Dolor, December, 2015.
- **Costa Rica:** Dr. Marco Ferrandino,\* palliative care specialist for adult patients, Centro Nacional de Control del Dolor y Cuidados Paliativos, Seguridad Social, December 2015.
- **El Salvador:** Dr. Marvin Colorado, palliative care specialist, Hospital de la Divina Providencia, December 2015.
- **Guatemala:** Dr. Marisol Bustamante,\* palliative care unit at the Unidad de Oncología Pediátrica, January 2016.
- **Panama:** Dr. Nisla Camaño, national coordinator of palliative care and of the Programa Nacional de Cáncer, Caja de Seguro Social, January 2016.
- **Uruguay:** Dr. Eduardo García Yanneo, clinical oncologist and palliative care specialist, April 2016.

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<sup>1</sup> Interviewees marked with an asterisk participated in the drafting of the *Atlas of Palliative Care in Latin America*.

**TABLE 1**  
**Socioeconomic indicators**

Country	Population	Per capita GDP	Human Development Index value	Human Development Index rank (out of 187)	Level of human development
Argentina	41,446,000	14,715	0.808	49	Very high
Chile	17,620,000	21,030	0.822	41	Very high
Colombia	48,321,000	11,890	0.711	98	High
Costa Rica	4,872,000	13,750	0.763	68	High
El Salvador	6,340,000	7,490	0.662	115	Medium
Guatemala	15,468,000	7,130	0.628	125	Medium
Panama	3,864,000	19,290	0.765	65	High
Uruguay	3,407,000	18,930	0.790	50	High

**SOURCE:** Prepared by the author with data from the Economic Commission for Latin America and the Caribbean (2015)

**TABLE 2**  
**Health system indicators**

Country	Population	Per capita GDP	Health spending per inhabitant	Percentage of GDP dedicated to health	Public health expenditure (% of total health expenditure)	Public health expenditure (% of total government expenditure)	Private health expenditure (% of total health expenditure)
Argentina	41,446,000	14,715	1,725	7.3	67.7	31.8	32.3
Chile	17,620,000	21,030	1,678	7.7	47.4	15.3	52.6
Colombia	48,321,000	11,890	843	6.8	76	16.1	24
Costa Rica	4,872,000	13,750	1,369	9.9	75	26.9	25
El Salvador	6,340,000	7,490	539	6.9	66.7	18.2	33.3
Guatemala	15,468,000	7,130	467	6.4	37.8	16.9	62.2
Panama	3,864,000	19,290	796	7.2	68.4	12.8	31.6
Uruguay	3,407,000	18,930	1,715	8.8	70.2	20.4	29.8

**SOURCE:** Prepared by the author with data from the Economic Commission for Latin America and the Caribbean (2015)

**TABLE 3**  
**Demographic and epidemiological indicators**

Country	Population	Population aged 60 years or older (% in 2010)	Population aged 60 years or older (% by 2050)	Total number of deaths due to non-communicable diseases (2012)	Number of deaths caused by non-communicable diseases, per 100,000 inhabitants (2012)
Argentina	41,446,000	14.4	24.1	255,400	467.3
Chile	17,620,000	13.5	33.0	79,100	366.5
Colombia	48,321,000	9.0	27.4	143,300	377.3
Costa Rica	4,872,000	11.2	30.8	17,600	391.8
El Salvador	6,340,000	9.7	23.4	26,400	474.9
Guatemala	15,468,000	6.6	15.4	37,600	409.4
Panama	3,864,000	9.8	23	13,400	372.9
Uruguay	3,407,000	18.5	27.8	26,200	446.0

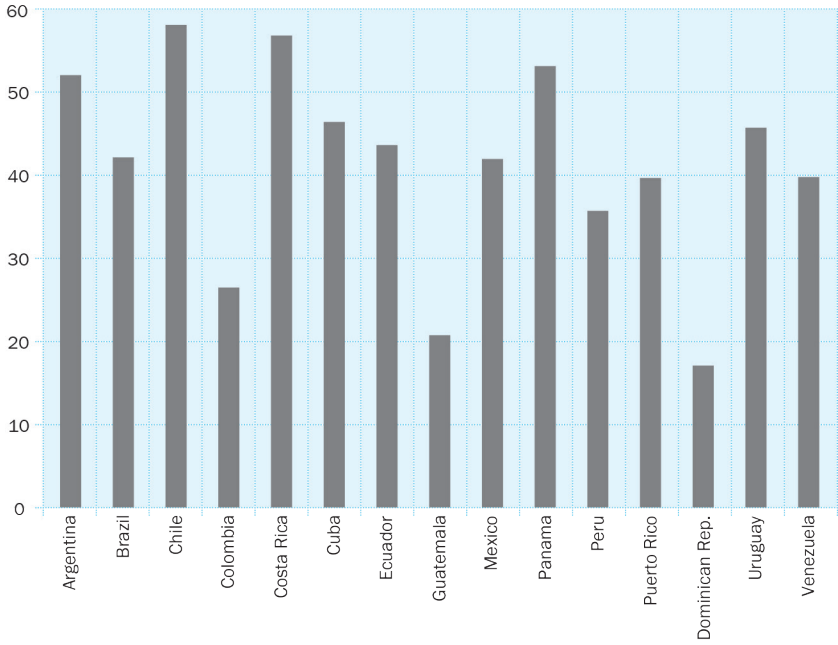
**SOURCE:** Prepared by the author with data from the World Health Organization (2013b) and the Economic Commission for Latin America and the Caribbean (2015)

**TABLE 4**  
**Palliative Care indicators**

Country	Population	Quality of death score (out of 100)*	Morphine consumption (mg/capita) (2013)**	Score: On a scale from 1 to 5, collaboration between prescribers and regulators (opioids)***	Signatory to Convention on Older Persons?
Argentina	41,446,000	52.5	7.30	4.0	Yes
Chile	17,620,000	58.6	2.49	4.0	Yes
Colombia	48,321,000	26.7	1.49	3.5	No
Costa Rica	4,872,000	57.3	3.62	5.0	Yes
El Salvador	6,340,000	N/A	0.31	2.0	No
Guatemala	15,468,000	20.9	0.04	2.0	No
Panama	3,864,000	53.6	0.22	3.5	No
Uruguay	3,407,000	46.1	4.32	3.7	Yes

**SOURCE:** Prepared by the author with data from the Economist Intelligence Unit (2015)\*, Pain and Policy Studies Group, University of Wisconsin/WHO Collaborating Center (2015)\*\*, and Pastrana et al. (2012)\*\*\*

**GRAPH 1**  
**Quality of Death Index: Scores from Latin America**



**SOURCE:** Economist Intelligence Unit (2015)

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