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CARE WHEN THERE IS NO CURE

Ensuring the Right to Palliative Care in Mexico

“[With the pain] I didn’t have the desire to do anything. I wasn’t hungry and didn’t want to walk...nothing. It would anger me when people spoke to me... [With palliative care] I have come back to life.”

– REMEDIOS RAMÍREZ FACIO, A 73-YEAR-OLD WOMAN WITH PANCREATIC CANCER WHO RECEIVES PALLIATIVE CARE AT MEXICO’S NATIONAL CANCER INSTITUTE.



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Summary

Almost 600,000 people die every year in Mexico, nearly half of them as a result of chronic illnesses such as heart and lung disease, diabetes, HIV or cancer. Hundreds of thousands more Mexicans battle with earlier stages of these and other chronic illness. Over the course of their illness many of these people experience debilitating symptoms such as pain, breathlessness, anxiety and depression. To ensure proper medical care for many of these individuals, access to palliative care and pain medicines is essential. Without these services, they will suffer needless pain and distress undermining their quality of life and that of their families in their final days of life.

In Mexico, access to palliative care services and to medicines essential for pain treatment is very limited. Human Rights Watch found that currently only a few dozen public healthcare institutions in the country offer palliative care and even fewer provide it in patients' homes. Most healthcare personnel have received no training in the discipline, and few doctors are licensed to prescribe strong pain medicines that are essential for palliative care. Where palliative care is available it is often due to the efforts of individual physicians or advocates rather than the result of a deliberate policy of the government, health system or insurer.

Palliative care seeks to control pain and other physical symptoms and address psychosocial and spiritual issues people with life-limiting illnesses and their families face. The World Health Organization (WHO) considers palliative care an essential part of the healthcare system and recommends that countries implement health policies to promote it, ensure adequate training of health professionals, and make essential palliative care medicines, including opioid analgesics, accessible. As palliative care does not require expensive equipment or medications it can generally be provided at a relatively low cost. A wealth of research studies has shown the effectiveness of palliative care and some studies have found that offering palliative care leads to overall cost savings for health systems due to reductions in the use of emergency health services and hospital admissions. The effectiveness of opioid analgesics, essential medicines for treatment of moderate to severe pain that are inexpensive and easy to administer, is equally proven, and in high income countries, they are widely available and used to address pain.

This report identifies challenges people with life-limiting illnesses in Mexico face accessing palliative care, with a special focus on access to pain treatment. The report is based on the research Human Rights Watch conducted in Mexico from 2011 to 2014, interviewing 115 patients, their family members, healthcare workers and government officials in Mexico City and the states of Chiapas, Jalisco, Mexico and Nuevo León. We also reviewed relevant legislation, insurance policies, medicines lists and other policy documents.

Seven of Mexico's thirty-two states—Coahuila, Guerrero, Hidalgo, Quintana Roo, Sinaloa, Tlaxcala and Zacatecas—do not have any known palliative care services. Another seventeen states have just one palliative care service, in the capital city in each case. For many Mexican residents, at the moment when they are most desperately ill, frail, and in intense pain, care is not available at all or only hours away by public transport. Opioid analgesics for chronic pain such as morphine are also almost completely unavailable outside state capitals.

As a result, many patients end up without access to palliative care, even if their insurance entitles them to such care. We found that in Mexico City and only three states (Durango, Guanajuato, and Jalisco), do patients with insurance from Mexico's largest three health insurers —Seguro Popular, the Mexican Social Security Institute (IMSS) and State's Employees' Social Security and Social Services Institute (ISSSTE)—have hospitals in their states that are both in their networks and offer palliative care and/or have a pain clinic.

In terms of training, only six of Mexico's 135 medical schools teach courses on palliative care for undergraduate medical students—these courses are mandatory in just two. As a result, many physicians and other healthcare workers do not have even basic skills in the care of patients who require palliative care.

The lack of availability of opioid pain medicines is due in part to insufficient training but also to complex prescription requirements that discourage physicians from obtaining the license needed to prescribe these medicines and pharmacies from stocking them. Mexico's health law requires physicians to use not just special prescription forms for opioid medicines but also barcoded stickers—an unusual requirement. These barcoded stickers can currently only be obtained in one place in every Mexican state and must be picked up in person, making this requirement highly burdensome to meet. This has

resulted in the vast majority of doctors, especially those living outside state capitals, not being authorized to prescribe these medicines. The government has announced it will replace this system to ensure easier access to barcoded stickers for physicians.

Even when patients find a physician able to prescribe these medicines, they face difficulties filling prescriptions. Very few pharmacies, especially outside state capitals, stock these medicines because almost no physicians outside state capitals can prescribe them and because of administrative requirements for licensing and record keeping. Furthermore, current dispensing regulations frequently force pharmacies to refuse to fill prescriptions on technical grounds forcing patients to return to their physicians to pick up new ones.

In January 2009, Mexico added a section on palliative care to its health law, granting people with terminal illness—defined as people with a prognosis of six months or less—the right to palliative care at healthcare institutions and at home. It grants them a right to information about their illness and prognosis and allows them to make decisions about medical care at the end of life, including a right to refuse life-prolonging treatment.

Under the law, all healthcare providers must develop treatment plans that address the individual needs of terminal patients and their families. Care must be provided by multidisciplinary teams that include not just physicians but also nurses, psychologists and other healthcare workers. The law obliges healthcare institutions to ensure that their personnel is adequately trained and that they have an adequate supply of medicines to treat pain and other symptoms.

These provisions of the health law were passed in recognition of the changing demographics and health burdens facing Mexico. While Mexico is still a relatively young nation, a rapid demographic shift is expected to occur in the next few decades. In 2010, only 7.1 million Mexicans were 65-years-old or older. By 2020, that number will reach 9.8 million, and by 2050, 23.1 million. Meanwhile the prevalence of chronic illnesses, such as cancer, heart disease and diabetes is on the rise and will continue to increase as a result of, among others, the aging process. By developing palliative care services now, Mexico's healthcare system can prepare itself for the wave of patients with chronic illnesses that will seek health services in years to come.

The palliative care provisions in the law are ambitious as they seek the full integration of palliative care into health services, but build upon Mexico's success in achieving near universal health coverage for its population through a combination of public, employer-based and private health insurance. Unfortunately, five years after the 2009 changes to the law, the intended results have yet to materialize.

The law requires a radical shift of the status quo. What is now ad hoc must become an integral part of the health system. This will require the development of the infrastructure within the health system capable of delivering palliative care; assigning and training sufficient numbers of healthcare workers; and the integration of palliative care into financing structures and insurance packages. It will also require changes in drug regulations and medicine policies to ensure the adequate availability and accessibility of opioid pain medicines. None of this can happen without the active stewardship of the Mexican government based on a step-by-step integration plan that identifies effective delivery models, puts into place the necessary regulatory framework to facilitate the process and holds institutions accountable for meeting requirements. Until recently, the government had not undertaken any of these steps.

However, in 2013, the situation began to change as both Mexican civil society and the government took up palliative care as a priority. A number of key meetings and an international seminar, organized by the Mexican Health Foundation (Fundación Mexicana para la Salud), the breast cancer organization Tómatelo a Pecho, and the National Autonomous University of Mexico served as catalysts for a number of important policy initiatives. Civil society has been able to work closely with high-level policy makers and leading legislators.

In November 2013, Mexico's president Enrique Peña Nieto signed a regulation that clarifies the content of a number of palliative care provisions in the health law. In March 2014, Health Minister Mercedes Juan López instructed her ministry to develop a national palliative care strategy. In March 2014, the ministry of health and the Federal Commission for the Protection against Health Risks (Comisión Federal para la Protección contra Riesgos Sanitarios, COFEPRIS), Mexico's regulatory agency for medicines, announced critical reforms to the system for prescribing and dispensing strong pain medicines, as well as record keeping. That same month, the National Commission for Social Protection in Health, which runs Seguro Popular, one of Mexico's largest health insurance programs, added a

number of key palliative care interventions to its package. It had previously not covered palliative care for most patients. Following an internal review, the Mexican Social Security Institute recently announced its intention to strengthen availability of palliative care within its system.

Finally, the health ministry is finalizing implementing norms for the 2009 amendments to the health law, which are expected to be released in October 2014, and the Public Health Council (Consejo Nacional de Salubridad) is preparing an agreement between different government agencies on the development of palliative care.

If these steps are properly implemented, Mexico seems poised for change. Its roll-out of universal health coverage provides a healthcare system into which palliative care can be integrated. Moreover, a number of successful models for the delivery of palliative care already exist. For example, under Governor Enrique Peña Nieto, Mexico's current president, Mexico State launched a state palliative care program in 2009 focused on developing decentralized services throughout the state and training healthcare workers, which resulted in the creation of palliative care units in nine hospitals around the state. Another key model was developed by a hospital of the Mexican Social Security Institute (IMSS), Mexico's largest health insurer, in Monterrey, Nuevo León, and allows patients to receive palliative care close to their homes through involvement of primary care providers.

These steps are in line with Mexico's obligations under international human rights law, which require it to take action to remove barriers facing patients who need access to palliative care. Both the International Covenant on Economic, Social and Cultural Rights, which Mexico ratified in 1981, and the prohibition of torture, cruel, inhuman and degrading treatment in the International Covenant on Civil and Political Rights, also ratified in 1981, can be understood as obligating the government of Mexico to act expeditiously to ensure access to palliative care and pain medicines. The well-being of hundreds of thousands of people in Mexico, who seek dignity and peace in their final days, depends upon the government accelerating action on the implementation of the 2009 health law reforms and realizing the goal of an integrated system of palliative care nationwide.

Recommendations

The implementation of the law will require a progression of actions that address several key challenges. First, the normative and conceptual basis for Mexico's palliative care system needs to be finalized. The law and regulation decide many big picture legal and conceptual questions but do not offer a specific model for the delivery of palliative care and leave a number of legal questions unresolved. Secondly, the healthcare system itself needs to be prepared to support and deliver palliative care services. This means that palliative care needs to be incorporated into insurance packages and financing structures and integrated into educational programs for healthcare workers. Finally, Mexico will need to build the delivery system for palliative care by setting up services, training existing healthcare workers and creating referral systems.

As noted above, the Mexican government has taken a number of encouraging steps to integrate palliative care into the country's health system. We welcome its commitment to ensure people with life-limiting illnesses do not have to face unnecessary suffering. To help make palliative care available to all people in Mexico who need it, we believe the following steps are essential:

Finalize Legal Base and Interpretation of the Law

The palliative care chapter in the health law leaves the interpretation of key provisions and guidance on implementation to the discretion of the health ministry. According to the law, the ministry was mandated to provide the official implementation norm by mid-2009 but has yet to do so. The ministry is currently finalizing the norm, which is expected to be published in October 2014. Among others, the norm should create a clear legal and conceptual basis to facilitate palliative care for adults and children in the home and by primary care providers.

The law currently does not cover palliative care for people with a prognosis of more than six months of survival. Yet, under international law these people have a right to palliative care if they meet clinical criteria for it. The government should reform the law to ensure these patients have access to adequate palliative care regardless of diagnosis or prognosis.

Develop Models of Care

The government needs to decide what model(s) of care should be used in public healthcare institutions in Mexico. In particular, it needs to determine:

- the role of primary care givers in the provision of palliative care;
- how home-based palliative care will be provided;
- what referral mechanisms should be put in place;
- how palliative care should be covered through health insurance policies; and
- what models of palliative care are most effective to meet the needs of children with life-limiting illnesses.

Adapt Healthcare System to Deliver Palliative Care

Based on the normative basis and models of care chosen, the government should take steps to prepare the health system to start delivering palliative care. Among key steps required are:

- adapt medicines lists to include all essential palliative care medicines;
- include palliative care interventions in insurance packages;
- implement the new system for prescribing opioid medications;
- include palliative care, including for children, in undergraduate training curricula for students of medicine, nursing, psychology, social work, and pharmacy.

Building the Delivery System

Finally, the government should ensure that the delivery system for palliative care is developed. To facilitate that process, it should:

- allocate funds to allow hospitals and clinics to set up palliative care services, referral systems, and train staff;
- specify requirements and timeframes hospitals and clinics must meet in rolling out palliative care.
- put in place a strong accountability system to monitor the development of palliative care by different parts of the system and allow for appropriate adjustments or other remedial action when requirements and timeframes are not met.

Methodology

This report is based on research conducted between September 2011 and February 2014, including field visits to Mexico in September and October 2011, February and April 2012, and February and October 2013. Field research was conducted primarily in the states of Jalisco and Chiapas as well as in Mexico City. We chose these locations for research because of their geographic diversity, with Jalisco situated in Western Mexico, Chiapas in the south, and Mexico City in Central Mexico. Additional research was conducted in the city of Monterrey, Nuevo León, a state in Northern Mexico. We also performed additional research in Mexico State because of its government's proactive efforts to develop palliative care. We also conducted extensive desk research regarding palliative care availability in various other parts of the country.

Over a cumulative total of eight weeks in Mexico, a Human Rights Watch researcher conducted 115 interviews with a wide variety of stakeholders, including 74 people with cancer, HIV/AIDS, and other life-limiting health conditions, or their relatives; 24 healthcare workers, including oncologists, anesthesiologists, palliative care doctors; 12 pharmacists or pharmacy personnel; and representatives of two pharmaceutical companies.

Interviews with patients and their relatives were conducted at their homes or in palliative care units at hospitals. Interviews were conducted in private whenever possible. Interviews were semi-structured and covered a range of topics related to palliative care and pain treatment. Before each interview we informed interviewees of its purpose, informed them of the kinds of issues that would be covered, and sought their consent before proceeding with the interviews.

Interviewees were informed that they could discontinue the interview at any time or decline to answer any specific questions, without consequence. No incentives were offered or provided to persons interviewed. We have disguised the identities of all patients, relatives and healthcare workers we interviewed in this report to protect their privacy, except when they specifically agreed that their real name could be used.

The Human Rights Watch researcher who led the research conducted almost all the interviews in Spanish, and was assisted by a Mexican psychologist with palliative care

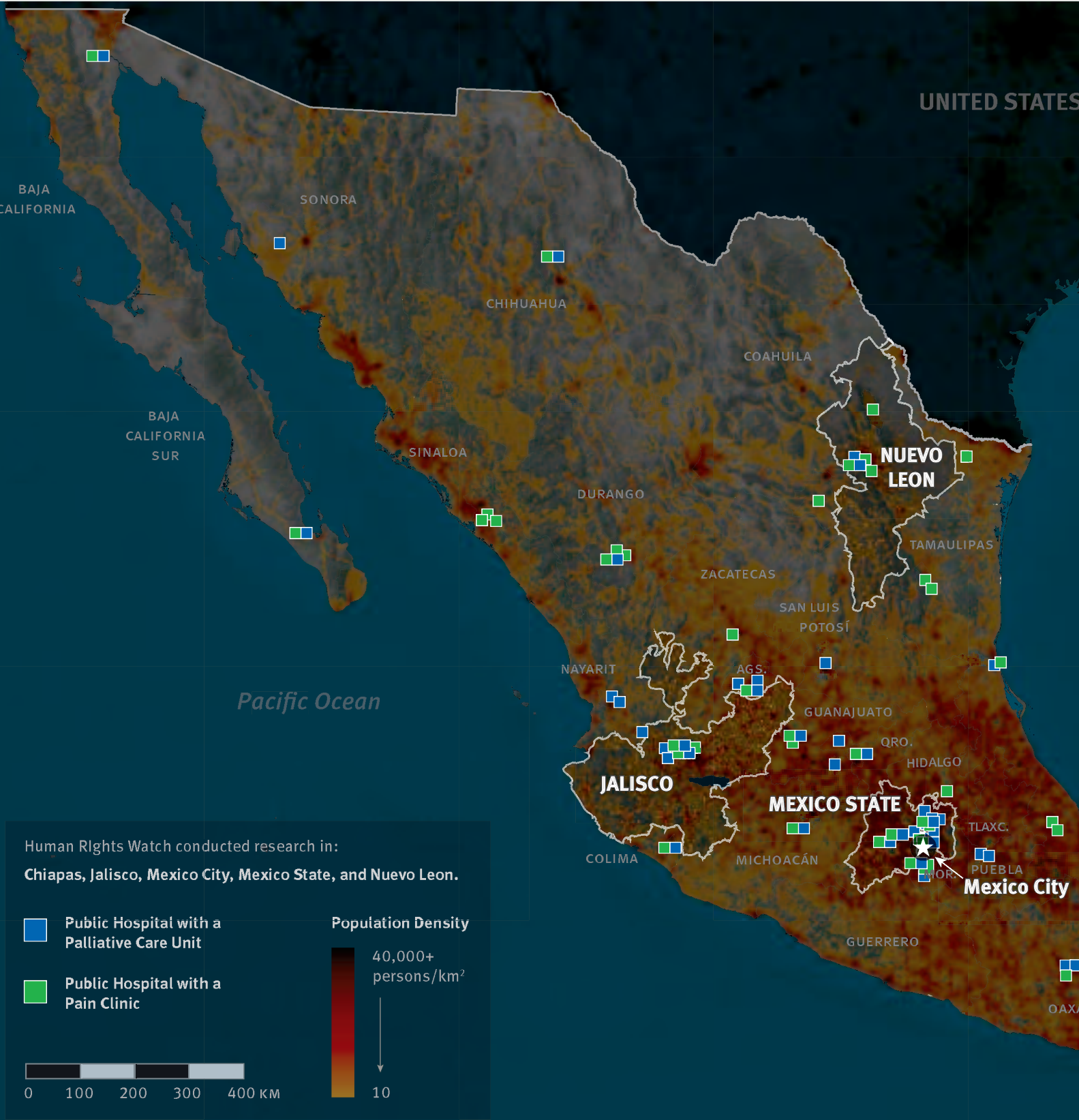
experience. A few interviews were conducted in English because the interviewee spoke English fluently.

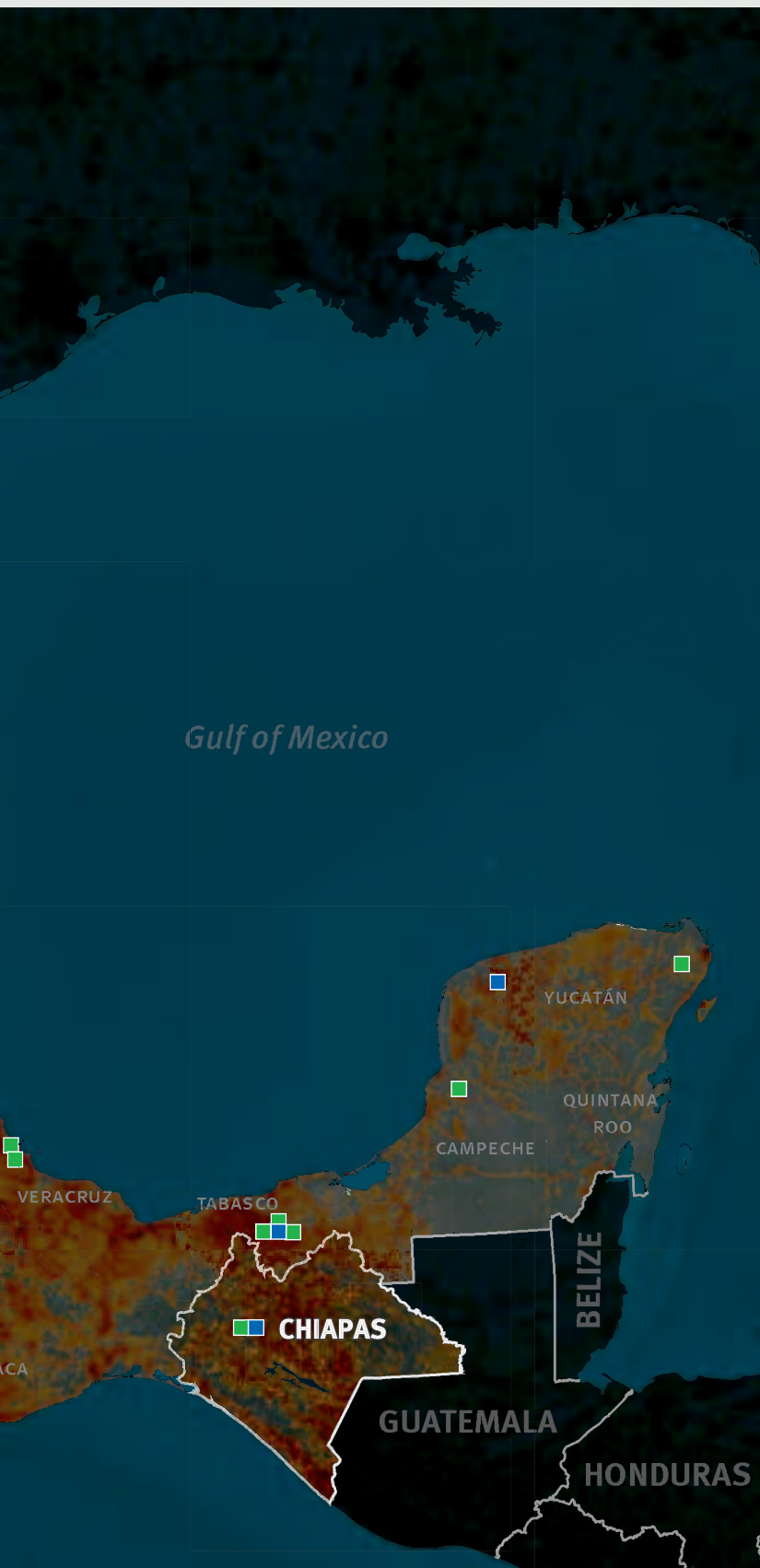
Human Rights Watch also submitted 24 requests for information under Mexico's freedom of information act, including one to Comisión Federal para la Protección contra Riesgos Sanitarios (COFEPRIS), one to the customs agency, and 22 to Mexico's states. We were unable to submit requests to the remaining nine states because their websites were either not functional or did not allow us to submit the requests. We received responses from COFEPRIS and 15 states. COFEPRIS' response also covered Mexico City and Nuevo León.

In June 2012, Human Rights Watch presented preliminary findings to the then minister of health, officials at the Federal Commission for the Protection against Sanitary Risks (COFEPRIS), and the National Commission for Social Protection in Health (NCSPH), which runs Seguro Popular. Between April 2013 and June 2014, Human Rights Watch presented preliminary findings to various officials of the new administration, including two deputy health ministers, the head of COFEPRIS, and officials at NCSPH, IMSS, and ISSSTE.

While the report focuses primarily on the availability of palliative care, various sections of this report examine the situation with pain treatment and pain clinics. Palliative care services and pain clinics are not the same. The former focuses not just on management of pain but also on other physical, psychosocial, and spiritual problems whereas the latter focuses not just on patients with life-limiting illnesses but also on those with acute or chronic pain problems.

All documents cited in the report are either publicly available or on file with Human Rights Watch.





I. BACKGROUND

THE IMPORTANCE OF PALLIATIVE CARE

Palliative care seeks to improve the quality of life of patients, both adults and children, facing life-limiting or terminal illness. Its purpose is not to cure a patient or extend his or her life. Palliative care prevents and relieves pain and other physical and psychosocial problems. Dame Cicely Saunders, the founder of the first modern hospice and a lifelong advocate for palliative care, points out that palliative care is about “adding life to the days, not days to the life.” The World Health Organization (WHO) recognizes palliative care as an integral part of healthcare that should be available to those who need it.¹ While palliative care is often associated with cancer, a much wider circle of patients with health conditions can benefit from it, including patients in advanced stages of neurological disorders, cardiac, liver or renal disease.²

One key objective of palliative care is to offer patients treatment for their pain. Chronic pain is a common symptom of cancer and HIV/AIDS, as well as other health conditions, especially in the terminal phase of illness.³ The WHO estimates that around 80 percent of both cancer and AIDS patients and 67 percent of both patients with cardiovascular diseases and chronic pulmonary diseases will experience moderate to severe pain at the end of life.⁴

Moderate to severe pain has a profound impact on quality of life. Persistent pain has a series of physical, psychological, and social consequences. It can lead to reduced mobility and consequent loss of strength; compromise the immune system; and interfere with a person’s ability to eat, concentrate, sleep, or interact with others.⁵ A WHO study found that people who live with chronic pain are four times more likely to suffer from depression or anxiety.⁶ The physical effect of chronic pain and the psychological strain it causes can even influence the course of disease, as the WHO notes in its cancer control guidelines, “Pain Can Kill.”⁷ Social consequences include the inability to work, care for oneself, children or other family members, participate in social activities, and find closure at the end of life.⁸

A wealth of research studies has shown the effectiveness of palliative care and some studies have found that offering palliative care leads to overall cost savings for health systems due to reductions in use of emergency health services and hospital admissions.⁹

According to the WHO, “Most, if not all, pain due to cancer *could* be relieved if we implemented *existing* medical knowledge and treatments” (original emphasis).¹⁰ The mainstay medication for the treatment of moderate to severe pain is morphine, an inexpensive opioid that is made of an extract of the poppy plant. Morphine can be injected, taken orally, delivered through an IV or into the spinal cord. It is mostly injected to treat acute pain, generally in hospital settings. Oral morphine is the medicine of choice for chronic cancer pain, and can be taken both in institutional settings and at home. Morphine is a controlled medication, meaning that its manufacture, distribution, and dispensing is strictly regulated both at the international and national levels.

Medical experts have recognized the importance of opioid pain relievers for decades. The 1961 Single Convention on Narcotic Drugs, the international treaty that governs the use of narcotic drugs, explicitly states that “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering” and that “adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”¹¹ The World Health Organization has included morphine in its Model List of Essential Medicines, a list of the minimum essential medications that should be available to all persons who need them, since it was first established.¹²

Yet, approximately 80 percent of the world population has either no or insufficient access to treatment for moderate to severe pain and tens of millions of people around the world, including around 5.5 million cancer patients and one million end-stage HIV/AIDS patients, suffer from moderate to severe pain each year without treatment.¹³

But palliative care is broader than just relief of physical pain. Other key objectives of palliative care may include the provision of care for other physical symptoms as well as psychosocial and spiritual care to both the patient and their family. Life-limiting illness is frequently associated with various other physical symptoms, such as nausea and shortness of breath, that

have significant impact on a patient’s quality of life. Palliative care seeks to alleviate these symptoms.

People with life-limiting illness and their relatives often confront profound psychosocial and spiritual questions as they face life-threatening or incurable and often debilitating illness. Anxiety and depression are common symptoms.¹⁴ Palliative care interventions like psychosocial counseling have been shown to considerably diminish incidence and severity of such symptoms and to improve the quality of life of patients and their families.¹⁵

The WHO has urged countries, including those with limited resources, to make palliative care services available. It recommends that countries prioritize implementing palliative care services in the community—providing care at people’s homes rather than at healthcare institutions—where it can be provided at low cost and where people with limited access to medical facilities can be reached, and in medical institutions that deal with large numbers of patients requiring palliative care services.¹⁶

In recent years, the WHO and the World Bank have urged countries to implement free universal health coverage to ensure that all people obtain the health services they need without suffering financial hardship when paying for them.¹⁷ Palliative care is one of the basic health services that the WHO and the World Bank say should be available under universal health coverage, along with “promotive, preventive, curative, and rehabilitative” health services.¹⁸

While Mexico is still a relatively young nation, a rapid demographic shift is expected to occur in the next few decades. In 2010, only 7.1 million Mexicans were 65-years-old or older. By 2020, that number will reach 9.8 million and by 2050 23.1 million.¹⁹ Meanwhile the prevalence of chronic illnesses, such as cancer, heart disease and diabetes is on the rise and will continue to increase as a result of, among others, the aging process. Thus, Mexico’s healthcare system can expect a wave of patients with chronic illnesses that will seek health services in years to come.

MEXICO'S HEALTHCARE SYSTEM

In 2003, Mexico reformed its healthcare system to provide insurance for millions of its uninsured citizens.²⁰ Following these reforms, it has achieved near universal health insurance coverage.

Prior to the reform, Mexico only provided health insurance through social security schemes targeted toward salaried workers in the formal sector of the economy and civil servants. Two social security programs—the Mexican Social Security Institute (IMSS) and the Institute of Social Security and Services for Government Workers (ISSSTE)—insured approximately 50 million people.²¹ Moreover, a small percentage of Mexicans were covered by private insurance.²² Yet, the social security schemes and private insurance left approximately half of Mexico's more than 110 million person population uninsured—principally low-income and unemployed individuals.²³

The uninsured faced impoverishing out-of-pocket costs, ill-defined benefits, and medicine shortages due to budgetary limitations.²⁴ Thus, as Dr. Julio Frenk, former Secretary of Health of Mexico, and others observed in an article in *Lancet*: “[The] Mexican health system was organized around a segmented model...and marked by the separation of health-care rights between the insured in the salaried, formal sector of the economy and the uninsured.”²⁵

Seeking to reduce and eventually eliminate segmentation in the provision of healthcare services, Mexico created Seguro Popular, a publically subsidized health insurance plan available to Mexicans not covered by a social security scheme or private insurance.²⁶ Seguro Popular provides a specific package of personal healthcare interventions and medicines at the primary and secondary levels of care.²⁷ As of 2014, the package—the Universal Catalogue of Health Services—contains 285 healthcare interventions.²⁸ Additionally, people covered by Seguro Popular are eligible to receive care for an enumerated list of complex medical procedures, including treatment for pediatric cancers and HIV, through the Fund for the Protection against Catastrophic Costs (Fondo de Protección contra Gastos Catastróficos).²⁹ As of 2013, Seguro Popular provided health insurance to approximately 55.6 million Mexicans.³⁰

Under the current healthcare system, each social security scheme and the Seguro Popular are vertically integrated. In other words, each insurance scheme maintains their own source of funds, service packages, and system of hospitals and clinics.³¹ The fragmentation of Mexico's insurance schemes creates disparate standards and operating norms at health institutions across the country.³² Moreover, since Mexico's health insurers do not cross-honor the policies of the other insurers, patients may be denied access to services at certain hospitals because of the type of insurance they hold.

¹WHO, “National Cancer Control Programmes: Policies and Managerial Guidelines, second edition,” 2002, <http://www.who.int/cancer/media/en/408.pdf> (accessed June 27, 2014), pp. 86-87.

²In a 2014 report, WHO listed the following conditions as potentially requiring palliative care: cancer, cardiovascular diseases, chronic obstructively pulmonary diseases, kidney failure, chronic liver disease, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, neurological diseases, Alzheimer’s disease and other dementias, congenital anomalies and infectious diseases such as HIV/AIDS and drug-resistant tuberculosis. WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” December 2013, http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf (accessed June 27, 2014), para. 7.

³Pain is also a symptom in various other diseases and chronic conditions and acute pain is often a side-effect of medical procedures. This paper, however, focuses on pain and other symptoms due to life-limiting illnesses.

⁴WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf, para. 7.

⁵Frank Brennan et al., “Pain Management: A Fundamental Human Right,” *Anesthesia & Analgesia* 105 (2007): 205-221, accessed June 27, 2014, doi:10.1213/01.ane.0000268145.52345.55.

⁶Oye Gureje et al., “Persistent Pain and Well-being: a World Health Organization Study in Primary Care,” *JAMA*, 280 (1998):147-151, accessed June 27, 2014, doi:10.1001/jama.280.2.147. See also B. Rosenfeld et al., “Pain in Ambulatory AIDS Patients. II: Impact of Pain on Psychological Functioning and Quality of Life,” *Pain* vol. 68 (1996), pp.323-328.

⁷WHO, “National Cancer Control Programme: Policies and Managerial Guidelines, second edition,” p. 83.

⁸Randall L. Daut et al., “Development of the Wisconsin Brief Pain Questionnaire to Assess Pain in Cancer and Other Diseases,” *Pain* 17 (1993): 197-210, accessed June 27, 2014, doi:10.1016/0304-3959(83)90143-4.

⁹Julie Hearn et al., “Do Specialist Palliative Care Teams Improve Outcomes for Cancer Patients? A Systematic Literature Review,” *Palliative Medicine* 12 (1998): 317-332, accessed June 27, 2014, http://medicine.emory.edu/ger/bibliographies/palliative/bibliography77_files/Do_speacialist_palliative_care_teams_improve_outcomes_for_cancer_patients.pdf; Rolfe Sean Morrison et al., “Cost Savings Associated with US Hospital Palliative Care Consultation Programs,” *Arch Intern Med* 168(2008):1783-1790, accessed June 27, 2014, doi:10.1001/archinte.168.16.1783.

¹⁰WHO, “Achieving Balance in Opioid Control Policy: Guidelines for Assessment,” 2000, p. 1.

¹¹United Nations Economic and Social Council (ECOSOC), “Single Convention on Narcotic Drugs of 1961, as amended by the 1972 Protocol amending the Single Convention on Narcotic Drugs, 1961,” preamble, http://www.incb.org/incb/convention_1961.html (accessed January 15, 2009).

¹²The 18th edition of WHO Model List of Essential Medicines, approved in 2013, is available at <http://www.who.int/medicines/publications/essentialmedicines/en/> (accessed June 13, 2014).

¹³WHO Briefing Note, “Access to Controlled Medications Programme,” April 2012, http://www.who.int/medicines/areas/quality_safety/ACMP_BrNote_GenrL_EN_Apr2012.pdf?ua=1 (accessed June 13, 2014).

¹⁴A 2006 literature review that compared prevalence of eleven common symptoms among patients with five advanced stage life-limiting illnesses found that studies reported depression prevalence of 3 to 77 percent in patients with advanced cancer, 10 to 82 percent in AIDS patients, 9 to 36 percent in patients with heart disease, 37 to 71 in patients with chronic obstructive pulmonary disease, and 5 to 60 in renal patients. For anxiety, reviewed studies reported prevalence of 13 to 79 percent in patients with advanced cancer, 8 to 34 percent in AIDS patients, 49 percent in patients with heart disease, 51 to 75 in patients with chronic obstructive pulmonary disease, and 39 to 70 percent in patients with renal disease. Joao Paulo Solano et al., “A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease,” *Journal of Pain and Symptom Management*, 31 (2006): 58-69, accessed June 27, 2014, <http://home.uchicago.edu/~tmurray1/research/articles/printed%20and%20read/a%20comparison%20of%20symptom%20prevalence%20in%20far%20advanced%20cancer%20AIDS%20heart%20disease%20chronic%20obstructive%20pulmonary%20disease%20and%20renal%20disease.pdf>.

¹⁵See, for example, WHO, “National Cancer Control Programme: Policies and Managerial Guidelines, second edition,” p. 83-91.

¹⁶WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf, paras. 19 and 20. See also WHO, “National Cancer Control Programmes: Policies and Managerial Guidelines, second edition,” <http://www.who.int/cancer/media/en/408.pdf>, pp. 91-92.

¹⁷ For the definition of universal health coverage, see http://www.who.int/health_financing/universal_coverage_definition/en/ (accessed June 3, 2014).

¹⁸ Ibid.

¹⁹ Consejo Nacional de Población (CONAPO). “Aspectos Generales de los resultados de las Proyecciones de Población.” Proyecciones de la Población 2010-2015o. CONAPO. 28 Nov 2012. See: http://www.conapo.gob.mx/es/CONAPO/Aspectos_Generales_de_los_resultados_de_las_Proyecciones_de_Poblacion (accessed June 27, 2014).

²⁰ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” *Lancet* 368 (2006):1524, accessed June 27, 2014, http://www.borderhealth.org/files/res_822.pdf.

²¹ Ibid., p. 1525; The World Bank, “The Mexican Social Protection System in Health,” 2013, <http://siteresources.worldbank.org/HEALTHNUTRITIONANDPOPULATION/Images/MexicanSocialProtectionSysteminHealth.pdf>, p. 2.

²² Felicia Marie Knaul et al., “Preventing Impoverishment, Promoting Equity and Protecting Households from Financial Crisis: Universal Health Insurance through Institutional Reform in Mexico,” *Innovations in Health Financing* (2005):25, accessed June 27, 2014, http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2050656; The World Bank, “The Mexican Social Protection System in Health,” <http://siteresources.worldbank.org/HEALTHNUTRITIONANDPOPULATION/Images/MexicanSocialProtectionSysteminHealth.pdf>, pp. 2-3.

²³ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” p. 1525; Felicia Marie Knaul and Julio Frenk, “Health Insurance in Mexico: Achieving Universal Coverage Through Structural Reform,” *Health Affairs*, 24 (2005), pp. 1467-68. In 2000, the World Health Organization ranked Mexico’s healthcare system 144 out of 191 countries in financial fairness. WHO, “The World Health Report 2000, Health Systems: Improving Performance,” 2000, http://www.who.int/whr/2000/en/whroo_en.pdf?ua=1 (accessed July 18, 2014), p. 153.

²⁴ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” pp. 1524-25; Felicia Marie Knaul and Julio Frenk, “Health Insurance in Mexico: Achieving Universal Coverage through Structural Reform,” *Health Affairs* 24(2005):1468, accessed June 27, 2014, http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688; Felicia Marie Knaul et al., “Preventing Impoverishment, Promoting Equity and Protecting Households from Financial Crisis: Universal Health Insurance through Institutional Reform in Mexico,” http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2050656, pp. 25, 49-50.

²⁵ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” p. 1525.

²⁶ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” p. 1524; Felicia Marie Knaul and Julio Frenk, “Health Insurance in Mexico: Achieving Universal Coverage through Structural Reform,” http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688, pp. 1468-1469.

²⁷ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” p. 1532; Felicia Marie Knaul and Julio Frenk, “Health Insurance in Mexico: Achieving Universal Coverage through Structural Reform,” http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688, p. 1470.

²⁸ The Universal Catalogue of Health Services (Catálogo Universal de Servicios de Salud) of March 2014 is on file with Human Rights Watch. At the time of this writing, the catalogue was not available online.

²⁹ Julio Frenk et al., “Comprehensive Reform to Improve Health System Performance in Mexico,” p. 1532; Felicia Marie Knaul and Julio Frenk, “Health Insurance in Mexico: Achieving Universal Coverage through Structural Reform,” http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688, p. 1470.

³⁰ Secretaría de Salud and Seguro Popular, “Sistema de Protección Social en Salud: Informe de Resultados,” 2013, p. 5. http://www.seguro-popular.gob.mx/images/Contenidos/informes/INFORME_DE_RESULTADOS_SPSS_2013.pdf (accessed on September 18, 2014).

³¹ Ibid., p. 14-15.

³² Ibid., p. 14-15.

REMEDIOS RAMÍREZ FACIO'S STORY

Remedios Ramírez Facio (73) lives on a small plot of land in Atitalaquia, a village in the state of Hidalgo in Central Mexico near one of the country's largest oil refineries.³³ She and her husband live in a small one-story brick building, painted bright orange, with corrugated roofs. In front, there is an open area with a table and some chairs where much of the family's life transpires. On the other side of their property live Ramírez's animals: dogs, chickens, ducks, and several large pigs. Closer to the road, a visitor's eyes are drawn to a colorful wall display of plants and flowers; these were more beautiful, Ramírez says, before she fell ill with cancer.

Ramírez and her husband have lived here for decades, raising all 7 of their children in their modest living quarters. Theirs is an impressive dynasty: 24 grandchildren, 19 great-grandchildren and 3 great-great-grandchildren, with several more on the way. The neighborhood around them is dotted with similar small houses where many of her children and their families live.

When a Human Rights Watch team visited Ramírez on a warm Sunday in late August 2014, she was full of energy. In the morning, she went to church, standing through an hour-long service. Upon returning home, she and her daughters prepared a big meal—it is tradition for the family to come together on Sunday afternoons. Even when most of the family sat down to eat, she kept busy, making sure everyone else was getting enough.

Her energy levels were remarkable for a woman whose pancreatic cancer has metastasized to her lungs and liver. Her condition was all the more notable given how she had felt a few weeks earlier. Suffering from severe abdominal pain and nausea, Ramírez had no energy. She could not sleep and had lost her will to live. Her daughter, Orlanda Hernández, said: "She didn't want to eat. She would tell us that it hurt. She was weak. We didn't see her improve. She was frustrated..."

Ramírez attributes her remarkable turnaround to the fact that she is now receiving palliative care at Mexico's National Cancer Institute. Before, she said, she had complained about pain to her doctors, but she had not received appropriate medications for it. In July 2014,



the local hospital in Hidalgo referred her to Mexico's National Cancer Institute; there physicians determined that she had pancreatic cancer that was not treatable



Doña Remedios Ramírez Facio, 73, who has pancreatic cancer, at her home in Atitalaquia, Hidalgo, Mexico, on Aug. 31, 2014.

Doña Remedios and her daughter, Orlanda Hernández Ramírez, 44, take a very early morning journey to receive palliative care at the National Cancer Institute in Mexico City, Mexico, on Sept. 1, 2014. They left their home before 5 a.m. and had to take multiple buses for a total journey of 4–5 hours.







Dr. Silvia Allende (back) and psychologist Leticia Ascencio speak with Doña Remedios about her illness, her prognosis, and her symptoms at the palliative care unit at Mexico's National Cancer Institute.

and they referred her to the palliative care unit. The physicians there assessed Ramírez's pain and other symptoms and put her on a small dose of morphine and nausea medication.

The impact of this simple invention was drastic. As Ramírez put it,

[With the pain] I didn't have the desire to do anything. I wasn't hungry and didn't want to walk...nothing. I felt very tired and didn't have the urge to do anything so I would lie down. I felt frustrated when people spoke to me. It would anger me when people spoke to me. [With palliative care] I have come back to life.

But there is a complication. In all of the state of Hidalgo, home to more than 2.5 million people, not a single public hospital offers palliative care. Ramírez's daughter told Human Rights Watch that she had recently taken her mother to the local hospital in Tula, the

closest town, because she was not feeling well; the doctors there had no idea what palliative care was and could not attend to her mother's needs.

Thus, Ramírez has to travel to Mexico City every few weeks to go to the National Cancer Institute, a trip that takes almost the entire day. Luckily, she usually does not have to go on public transport; the local community clinic tries to make an ambulance available—for payment—to people who need to travel to hospitals in Mexico City for medical care.

Even so, the trip to Mexico City is long. The ambulance, which collects multiple patients and drops them off at different hospitals all over Mexico City, picks up Ramírez at around 4:30am so they can get to the hospital in time for the appointment. The ambulance usually does not get her back home until around 4:30pm. The round-trip cost—200 pesos (about US\$15)—is more than Ramírez and her husband normally spend in weeks.

On September 1, Ramírez had an appointment at the hospital, but the ambulance was not available. So she and her daughter had to travel by public transport. They left home shortly before 5am to walk 45 minutes through the darkness to the closest bus stop. As her daughter described the journey:



To get to the cancer hospital, we need to take a combi [a small bus]. Then we take a bus that takes us to the bus depot. We then get another bus that takes us to Taxqueña. In Taxqueña, we get yet another bus that takes us to the hospital. There are four buses from here to there.

Even with help from the Human Rights Watch team, which was filming Ramírez’s journey and took her part of the way by car, the trip was arduous. Upon arriving at the hospital, Ramírez said: “I get very tired travelling all the way.”

On the day we accompanied her, Ramírez was in fairly good health. As her illness progresses, however, her condition is likely to deteriorate, making the trip—by ambulance or public transport—increasingly difficult. Indeed, many people with illnesses like Ramírez’s can no longer make the journey at some point. In such cases, the hospital recommends that relatives go by themselves to pick up prescriptions and medicines. But when the palliative care team is no longer able to speak with and examine the patient, the care they are able to provide is limited.

Doña Remedios shows a doctor and a psychologist at the palliative care unit at Mexico’s National Cancer Institute how much regular morphine injections have reduced her pain. On the scale, her pain has gone from “I can’t tolerate the pain” to “it hurts a little.”

But on September 1, Ramírez made it to the hospital and was able to benefit from the services it offered, and meeting a physician, psychologist and nutritionist. The physician extended her prescription for morphine and added a medication for a cough that had started bothering Ramírez a few days earlier. The physician and psychologist also spoke openly with Ramírez about her illness and her prognosis—a tough conversation during which she tearfully expressed her anxiety over leaving behind her children, especially her son who, due to a recent accident, is in a wheelchair.

No matter how difficult it was to face her own mortality, Ramírez left the hospital in an upbeat mood. She said she felt grateful that the doctors had spoken with her openly and with empathy: “It gives me more desire to live.”



Doña Remedios and her daughter at the pharmacy of the National Cancer Institute in Mexico City, Mexico on Sept. 1, 2014 to fill a prescription for morphine. They have to travel for several hours to procure the medication because there are no hospitals with palliative care in Hidalgo, their home state.

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A portrait of Don Pedro Preciado Santana graces the living room of the Preciado Santana family.

PEDRO PRECIADO SANTANA'S STORY

Pedro Preciado Santana, the 65-year-old owner of a carpentry shop in Guadalajara, Mexico, was a vivacious man. He loved sitting on the porch outside his home in the afternoons, waving and chatting with friends and neighbors passing by, and watching the park across the street. His daughter, Adriana Preciado Pérez, said everybody in their neighborhood knew him.³⁴

In January 2010, an incapacitating pain in Preciado Santana's shoulder rudely interrupted this daily routine. His daughter told Human Rights Watch that, at times, her father would turn completely white, his blood pressure would drop and he would break out in a sweat. Sometimes the pain was so severe that his family would rush him to the emergency room.

Doctors struggled to determine what caused the discomfort. After numerous fruitless visits to public and private clinics, a neurosurgeon recommended surgery in July 2010 for what he thought was a compressed vertebra. However, the surgical intervention did nothing to diminish the pain. In fact, that fall, Preciado Santana's pain worsened and he repeatedly contracted pneumonia.

Preciado Santana underwent more medical exams and eventually his doctors found a malignant tumor in his right lung. Despite the grim diagnosis, Preciado Santana decided to fight. "My father loved life and he wanted to do everything possible," his daughter said. "He didn't choose to go. He was taken away from us." Two courses of chemotherapy and radiation at Centro Medico Nacional de Occidente, a hospital of the Mexican Social Security Institute (IMSS) where Preciado Santana was insured, managed to reduce the size of the tumor significantly, and his pain diminished as well. But doctors thought that his immune system was too compromised for him to undergo a third round of chemotherapy and radiation; they told Preciado Santana that his case was terminal and that he had run out of options.

Although he could no longer be cured, Preciado Santana's healthcare needs were possibly greater than ever before in his life. As the cancer grew, and spread, Preciado Santana experienced ever more severe pain, as well as various other symptoms. Due to emphysema, a destructive process in the lungs, he was con-



Adriana Preciado Pérez in her parents' house, discussing her struggle to ensure her father received proper care at the end of his life at a public hospital. She eventually engaged a palliative care physician from a private hospital to attend to him, allowing him to die peacefully in his home.

stantly gasping for air. Preciado Santana struggled emotionally with his prognosis and became increasingly depressed. These are all symptoms that can be controlled well through palliative care.

Preciado Santana's hospital, however, did not have a palliative care service. As a result, he and his family had to navigate their way through this very difficult period with little or no professional guidance and very little help from the hospital. Without anyone in his hospital seeking to coordinate his case, the care he received was highly fragmented, often inadequate, and required numerous hospital visits even as travel became difficult and painful. In fact, his last few months he and his family struggled not only with his disease but also with the very healthcare system that was supposed to care for him.

For example, Preciado Santana's daughter would take him to the pain clinic at the hospital in his wheelchair with his oxygen tank before 7:00 a.m. to take his place in a cramped unventilated waiting room that tended to be full of other patients, some of whom were acutely ill. Sometimes, she said, her father would wait for six hours before the doctor could finally see him. Moreover, only one doctor at the hospital could renew his prescription for morphine. On several occasions, Preciado Santana's daughter had to return at a later time or date to get the prescription because that doctor had left for the day.

Even in the advanced stages of his illness, when the trip to the hospital had become very difficult because of severe swelling, bed sores and skin problems, the doctors at the pain clinic insisted that Preciado Santana come in person. His daughter said: "When I told the doctor that I could not take my father to the hospital anymore, the doctor responded: 'If you don't bring him, we won't give him the medicines.'" With no other choice, she continued to bring him to the hospital in their private car. She said: "I would drive slowly. Any bump, any pothole hurt him."

When Preciado Santana's daughter noticed that her father was becoming increasingly introverted—he stopped being his talkative self—and depressed, she



requested a consult with a psychologist. However, the psychology department could not schedule the appointment until four months later. By that time, Preciado Santana was too ill and weak to be able to benefit from the psychologist's services.

As time went by, the severity of Preciado Santana's pain kept increasing and the morphine dosages that doctors at the pain clinic prescribed became insufficient to control it. Yet, the doctors at the clinic were reluctant to increase the dose. His daughter told Human Rights Watch: "They treated me as if I was trying to sell the morphine; they were never able to control his pain."

Although the hospital had a home-based care service for the chronically ill, this service was not adapted to the needs of patients with limited life expectancy. When Preciado Santana's daughter inquired about enrolling her father, she was told it could not take new patients for a period of several months. An opening was eventually available, but it was too late; as Preciado Santana had already died.

Disillusioned by the quality of the services provided by the hospital, Preciado Santana's daughter began searching for other options to get proper care for her dying father. In May 2011, the director of a private hospice advised her to see Dr. Gloria Domínguez, who

Adriana Preciado Pérez, 40, with her younger sister, Martha Elizabeth Preciado Pérez, 30 and their mother, Guadalupe Teresa Pérez López, 69, at their home in Guadalajara, Mexico on Aug. 30, 2014. The father of the family, Don Pedro Preciado Santana, died of cancer in September 2011.

leads an integrated palliative care team at Hospital Dr. Ángel Leaño of the Autonomous University of Guadalajara. Her team accompanied Preciado Santana and his family in the last few months of his life, visiting him at his home and advising his daughter by telephone whenever new symptoms or complications arose. Although his daughter had to continue taking him to some follow up appointments at Centro Medico for insurance reasons, the family could now rely on the palliative care team in the day-to-day care of Preciado Santana.

The difference, his daughter said, was enormous. Dr. Domínguez and her team attended to all her father's needs at once, providing medical treatment, psychological support and guiding the family in taking care of him at home. By helping the family understand what they could expect to happen as Preciado Santana drew

closer to his death and how they could respond, the team also gave the family, in Adriana Preciado's words, "enormous peace of mind."

Preciado Santana eventually passed away in September 2011 in his home, as had been his express wish.



Dr. Gloria Domínguez Castillejos, director of the palliative care unit at Hospital Doctor Ángel Leño, a private hospital, in Guadalajara, Mexico on Aug. 29, 2014. Domínguez cared for Don Pedro Preciado Santana during his last few months.



³³ This case study is based on interviews with Remedios Ramírez Facio and her daughter Orlanda, August 31 and September 1, 2014, in Atitalaquia, Hidalgo, and Mexico City.

³⁴ Human Rights Watch interview with Adriana Preciado Pérez, February 22, 2012, Guadalajara.

II. The Experiences of People in Need of Palliative Care

Almost 600,000 people die every year in Mexico, nearly half of them as a result of chronic illnesses such as heart and lung disease, diabetes, HIV or cancer.³⁵ Hundreds of thousands more Mexicans battle with earlier stages of these and other chronic illnesses. Over the course of their illness many of these people experience debilitating symptoms such as pain, breathlessness, anxiety and depression. To ensure proper medical care for many of these individuals access to palliative care and pain medicines is essential. Without these services, they will suffer needless pain and distress undermining their quality of life and that of their families in their final days of life.

Over the course of our research, we collected testimony from dozens of patients and their families about the challenges they faced accessing palliative care. While a few patients reported having access to comprehensive palliative care, the overwhelming majority of patients had no access to palliative care whatsoever or accessed care only with great difficulty, delays or with frequent disruptions.

Availability of Palliative Care across Mexico

Human Rights Watch estimates that many thousands of people in Mexico have no access to palliative care whatsoever as this service remains unavailable in most parts of the country, especially outside state capitals. A review of two recent studies of palliative care services and pain clinics, presented in Appendix 1, shows that seven of Mexico's thirty-two states—Coahuila, Guerrero, Hidalgo, Quintana Roo, Sinaloa, Tlaxcala and Zacatecas—with a combined population of almost 16 million people do not have any known palliative care services in the public healthcare system; one of those states, Tlaxcala, does not have any hospitals with a pain clinic either.³⁶ Another seventeen states have just one palliative care

³⁵ Statistics from Instituto Nacional de Estadística y Geografía, <http://www3.inegi.org.mx/sistemas/sisept/Default.aspx?t=mdemo107&s=est&c=23587> (accessed June 27, 2014).

³⁶ The National Health Council (Consejo Nacional de Salud) conducted one study; the Latin American Palliative Care Association the other. The Consejo Nacional de Salud sent a questionnaire to health authorities in all states requesting information on public hospitals that have pain clinics or palliative care units. All but two states—Chiapas and Puebla—responded. The Consejo did not conduct follow-up verification of responses but noted to Human Rights Watch that the responses came from the official health authorities. The Latin American Palliative Care Association sought to identify all palliative care services in México through surveys of key informant interviews. The findings of the latter study can be found at: http://cuidadospaliativos.org/uploads/2012/10/atlas/15_México.pdf (accessed June 13, 2014). Some additional changes were made to the list based on new information. The table may not accurately reflect the availability of palliative care in hospitals that have integrated it into their services without creating a formal palliative care unit. These studies also did not survey primary health providers on whether they have integrated palliative care into their general care for patients. However,

service, in each case in the capital city. Just five of Mexico's states—Guanajuato, Mexico State, Nuevo León, Tamaulipas, and Veracruz—have palliative care services and/or pain clinics available in multiple cities. The overview map shows the distribution of palliative care services and pain clinics around the country.

Only in Mexico City do palliative care services exist in at least one hospital of each of Mexico's three largest insurers, IMSS, ISSSTE, and Seguro Popular. Durango, Guanajuato and Jalisco are the only three states in which there are hospitals associated with these three insurers that have a palliative care service and/or pain clinic. Ten other states have a palliative care service or pain clinic in hospitals associated with two of these three insurance providers. As Mexico's health insurers do not cross honor each other's policies, even in states where palliative care is available in some hospitals, many people who need it may still not have access because they do not have the right insurance.

As the overview map shows, the situation is particularly dire for people who live outside of state capitals. In both Chiapas and Jalisco, two of Mexico's larger states, there are dozens of large and midsized towns that do not have any palliative care services or pain clinics. Our research found that in Chiapas, Jalisco and Nuevo León, palliative care was almost exclusively concentrated in capital cities (see Table 1). The state maps, see Section entitled "Accessing Strong Pain Medicines", demonstrate visually how far people in communities all over these states must travel to access palliative care and pain treatment. By contrast, in Mexico State, where there are palliative care units in hospitals in seven different cities, the distances are significantly smaller.

leading palliative care advocates in México who have done a lot of training of physicians believe the number of primary care providers that have done so to be very low.

Table 1 – Assessing Availability of Palliative Care in Chiapas, Jalisco and Nuevo León

State	Hospitals in public healthcare system ³⁷	Number with palliative care service and/or pain clinic	Number with pain clinic but no palliative care unit
Chiapas	59	1	1
» Tuxtla Gutiérrez	7	1	1
» Rest of state	52	0	0
Jalisco	69	4	3
» Guadalajara	22	4	3
» Rest of state	47	0	0
Mexico State	114	10	0
» Toluca	17	4	0
» Rest of state	97	6	0
Nuevo León	32	2	4
» Monterrey	16	2	2
» Rest of state	16	0	2

Ximena Pérez’s Story

Ximena Pérez was a 57-year-old mother and grandmother who lived with several of her children, grandchildren, and some animals in a home just outside of San Cristóbal de las Casas, a city in Chiapas.³⁸ She worked in a bakery until she became ill in 2012. Pain in the right side of the stomach was the first sign that something was wrong. Pérez initially thought she had a bout of gastritis, but when the pain did not subside she decided to seek medical help. A local doctor examined her and discovered that she had a significantly enlarged gallbladder. A subsequent tomography found a tumor in her liver.

The physician referred Pérez to a surgeon at a local general hospital to see whether the tumor could be removed. Her family scheduled an appointment. By the time of the appointment, Pérez’s pain had become very severe. She told a Human Rights Watch

³⁷ We established the number of hospitals in each state using the ministry of health’s database of healthcare institutions (<http://plataforma.salud.gob.mx:8091/>), searching for “unidad de hospitalización” among the following institutions: IMSS, ISSSTE, Secretaría de la Defensa Nacional, Secretaría de Marina, Secretaría de Salud, and Universitario.

³⁸ Human Rights Watch interview with Ximena Pérez (pseudonym), San Cristóbal de las Casas, Chiapas, April 28, 2014.

researcher: “[It was there] the whole day, the whole day...In truth, I could not bear it anymore.” She added that she could no longer sleep for more than about a half hour at a time.

When Pérez got to the hospital, an unpleasant surprise awaited her. The surgeon was not there so the appointment had to be rescheduled a full month later. Pérez told the hospital staff that she was in severe pain but only received pain medicines that are routinely sold over-the-counter in pharmacies and are not recommended for use for more than a few days because of its side effects. Pérez’s daughter said:

My mom came [to the hospital] in a lot of pain but they didn’t pay attention...They only gave her ketorolac but that did not control the pain...I asked the doctor what my mom had...We were told to wait for the appointment with the oncologist...The appointment was canceled and another was scheduled for a month later...But my mother spent a lot of time in pain.

Pérez herself said that “when I left [the hospital] I left crying because it hurt [so much].”

The family learned about a pain clinic in Tuxtla Gutiérrez, the capital of Chiapas, but Pérez’s state of health was too bad for her to be able to make a trip that would take almost a full day. Family members told a Human Rights Watch researcher that they were at a loss as to what to do.

A few weeks before our interview, a neighbor told the family about a primary care physician in San Cristóbal who was specializing in pain and palliative care. The family made an appointment with the doctor who examined her and prescribed opioid pain medicines. Pérez told Human Rights Watch: “I thank God for this doctor because with this [medicine] I can tolerate it.”

In Search of Palliative Care

Dozens of the patients we interviewed had managed to access palliative care at the time of the interview but said that they had faced significant delays—often months—in getting this care. In most of these cases, the hospitals where they sought care did not offer palliative

care but did not refer them to providers that did. As a result, they struggled with symptoms that were inadequately controlled until they eventually found a palliative care provider on their own.

These people often described increasingly desperate searches for better care options and eventually, frequently through word-of-mouth and often very late in the illness, ended up with a palliative care program. For example, Guadalupe Herrera who has advanced diabetes described having significant neuropathic pain for over a year. She said that she has trouble putting on shoes because of a burning sensation in her feet: “It is as if someone is putting needles in my feet.” She told a Human Rights Watch researcher:

I went back to the local clinic when weak pain medicines did not work. They told me the burning is because of diabetes. It's like they told me I would have to live like this [with the pain], that there was no remedy...The pain makes me feel depressed. My state of mind is much affected by the pain. I'm a big cry baby but sometimes it hurts so much.³⁹

There are manifold reasons for these kinds of delays in the provision of palliative care: physicians may feel that they are able to provide adequate care themselves despite not having any training in palliative care; they may be reluctant to refer patients to other departments at their hospital or to other institutions; the absence of referral protocols and information about hospitals that have palliative care complicates referrals as do the lack of cross-honoring of health insurance and the absence of any palliative care services at any nearby hospital.

The situation at a specialized pain and palliative care institution in the Zapopan area of Guadalajara offers a particularly vivid example of how the lack of a referral system and late referrals lead to unnecessary suffering. Instituto Jalisciense de Alivio al Dolor y Cuidados Paliativos (Instituto Palia) is an institution of the Jalisco state government that offers pain management and palliative care to patients irrespective of their insurance status. It has several multidisciplinary teams that visit patients in the metropolitan area of Guadalajara in their homes to provide them palliative care. It is a unique institution in Mexico that

³⁹ Human Rights Watch interview with Guadalupe Herrera (pseudonym), Guadalajara.

offers a service—full-fledged home-based care by a team consisting of a physician, nurse, social worker and psychologist—that few other institutions in the country can match. Yet, according to Instituto Palia’s staff, fewer than 50 percent of its patients come via referral by doctors at other institutions. While the institute does not collect data on referral sources, all physicians at the institution we interviewed lamented the fact that so few doctors at other hospitals referred patients directly to them—or did so very late—despite not having the capacity to care for the patients properly themselves. Dr. Rosa Margarita Álvarez, one of those physicians, commented: “The majority of our patients are referred by other patients or someone else [not doctors]. Eighty percent come with pain that has not been treated properly.”⁴⁰ Dr. Karla Madrigal, another physician at the institute, told Human Rights Watch:

Very frequently patients are referred late. Often, people come to us on their death bed. When you go [to their homes] the next day the patient is already dead. They are sent at the very end...They [the relatives] are desperate, someone tells them about us...⁴¹

María García’s Story

When we interviewed María García, a woman of around 70, she lived in a modest home in San Juan de los Lagos, a small town in Jalisco, with her husband, youngest daughter and baby grandchild.⁴² She had been completely bedridden for two years as the result of a metastatic tumor in her back that had left her paralyzed.

She had become ill a few years earlier when she developed pain in her leg, which later extended to her spine. She tolerated the pain for some time but eventually went to the doctor who discovered tumors in her back and leg. García underwent surgery to amputate part of one leg and remove the tumor in her back. The operation caused damage to the nerves in her spinal cord, which left her unable to walk.

García had a series of health needs, ranging from increasingly severe pain to skin care—people who are bedridden often develop bed sores—to psychosocial care. While María had

⁴⁰ Human Rights Watch interview with Dr. Rosa Margarita Álvarez, November 14, 2011, Guadalajara.

⁴¹ Human Rights Watch interview with Dr. Karla Madrigal, November 14, 2011, Guadalajara.

⁴² Human Rights Watch interview with María García (pseudonym), February 25, 2012, San Juan de los Lagos, Jalisco.

insurance through Seguro Popular, the local hospital in San Juan de los Lagos did not offer palliative care. Her doctor prescribed analgesics but they were not strong enough to control her pain. García needed morphine or another opioid pain medicine but San Juan de los Lagos did not have physicians who prescribe these or pharmacies that sell them. García told Human Rights Watch researchers that her pain was very severe. She said:

I almost faint. I feel like it's going to give me a heart attack...It's like electrical charges from where I have the prosthesis. I have shocks that go up and down. I scream, I cry. I don't know what I do.

Unable to get proper care locally, García's family took her to Aguascalientes and Guadalajara, a difficult one-and-a-half hour journey for a woman who is paralyzed and in severe pain. A hospital in Guadalajara provided García with a morphine infusion pump that helped her control her pain.

By the time we interviewed her, however, García was no longer able to travel to Guadalajara for check-ups. Her aging husband had to travel once a month to the hospital there in order to buy a new supply of morphine, which is not covered under Seguro Popular. The palliative care team at the hospital in Guadalajara had to manage García long distance and make adjustments to her treatment without being able to examine her.

The Hardship of Travel

We encountered this scenario repeatedly in our interviews, of people with terminal illnesses—and often in rapidly deteriorating condition—traveling long distances, sometimes as long as six to eight hours on a bus, in order to receive palliative care or receiving it remotely. With no hospital close to home offering palliative care—or no system to refer patients to hospitals that do—these people faced the unenviable choice between traveling long distances, often on rickety buses, in order to access palliative care or asking relatives to do the traveling for prescriptions and receiving suboptimal care.

This scenario is very common for the simple reason that diagnosis and curative treatment for life-limiting illnesses is often available only at tertiary care institutions. As primary care physicians do not have the equipment or knowledge to treat cancer or heart disease, for example, they generally refer patients to secondary care institutions as soon as they

suspect a serious condition. In many cases, that process repeats itself at the secondary care level and patients are referred to a specialist hospital. With each referral the distance patients must travel to access treatment increases, as specialized hospitals tend to be located only in major metropolitan areas.

For curative care, the cost and inconvenience of such travel may be unavoidable as primary and many secondary care facilities do not have the specialists, diagnostic equipment, laboratory capacity, and treatment options available to properly manage patients with complex illnesses. This is not true, however, for palliative care, which for most patients does not require any complex interventions and can be provided at lower levels of care. Moreover, as we have seen in several of the testimonies above, for people with terminal illness travel is extremely difficult, making it all the more important that palliative care be available close to or in the home.

When people who are terminally ill can only access palliative care by travelling long distances to tertiary care hospitals the central objective of this care—safeguarding the dignity of these people—is not achieved. Mexican legislators were clearly mindful of that fact when they adopted the amendments to the health law and explicitly included a right to receive palliative care in the home. Yet, palliative care services have not been decentralized sufficiently to allow people to receive it in or close to their homes.

We encountered this scenario over and over again when at Mexico's National Cancer Institute (NCI) in Mexico City. We interviewed multiple patients who were in their last weeks of life and arrived at the hospital in a terrible state after traveling for hours on buses. In some cases, relatives carried their loved ones wrapped in blankets from the bus or taxi to the hospital because the patient could no longer walk or stand. We also interviewed numerous relatives of patients who were no longer able to make the trip to the NCI. In such cases, the palliative care team had to adjust treatment decisions based on descriptions by relatives rather than on examination of the patient. Often, the care offered was reduced to just renewing prescriptions. Better than being left without care but far from the quality of care patients should receive.

In 2012, the palliative care service at the NCI conducted a review of the cases of 600 incurable cancer patients attended in 2010, many of whom had lived outside Mexico City. The review found that almost 30 percent of patients attended the service only once, even

though all were given a follow-up appointment.⁴³ While the study did not establish the reasons why patients did not return, the NCI’s doctors believed that a significant proportion were unable to return because they were too ill to travel or lacked the financial resources to do so.⁴⁴

Accessing Strong Pain Medicines

“[I have a pain all the time but] when food goes into my colon I cannot tolerate the pain. It is like a bomb...In the hospital, I was told to endure the pain.” – Liliana Arroyo, a patient with colon cancer⁴⁵

Pain treatment is a critical component of palliative care and our research specifically examined the availability and accessibility of strong analgesic medicines. Although strong analgesic medicines like morphine are relatively inexpensive, we found that these medicines are often difficult to access because few physicians are trained in using them and because they are controlled substances and thus subject to special regulations.

The experiences of people we interviewed point to a gaping divide between the availability of pain medicines for people who live in major metropolitan areas or state capitals and those who live in smaller towns and rural areas. For the latter, accessing opioid analgesics is enormously difficult because very few doctors outside of state capitals seek licenses to prescribe them and almost no pharmacies sell these medicines. People in state capitals generally had better access to doctors able to prescribe these medicines but frequently encountered difficulties filling prescriptions because of strict rules and shortages of medicines.

The government has announced steps to try to resolve many of the problems our research identified. For discussion, see Chapter V.

⁴³ Allende-Perez, S., Mohar A., De La Garza J., Herrera A., Meneses A., Verástegui E., “Care for All: Palliative Care Strategy to Provide Intensive Acute Symptom Control Management for Patients with Previously Undiagnosed Terminal Cancer at the Instituto Nacional de Cancerología in México City,” *Journal of Palliative Care and Medicine*. In press.

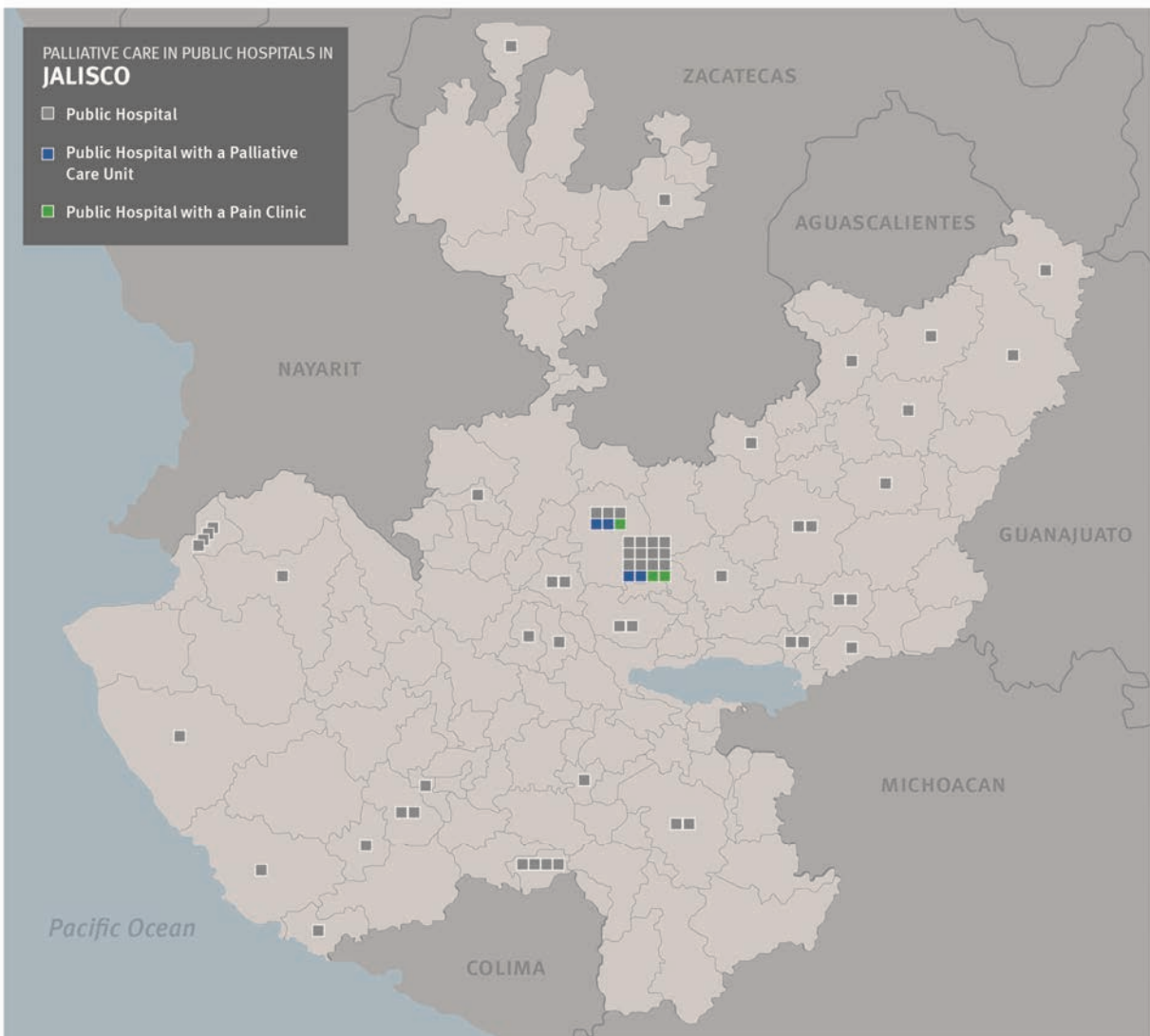
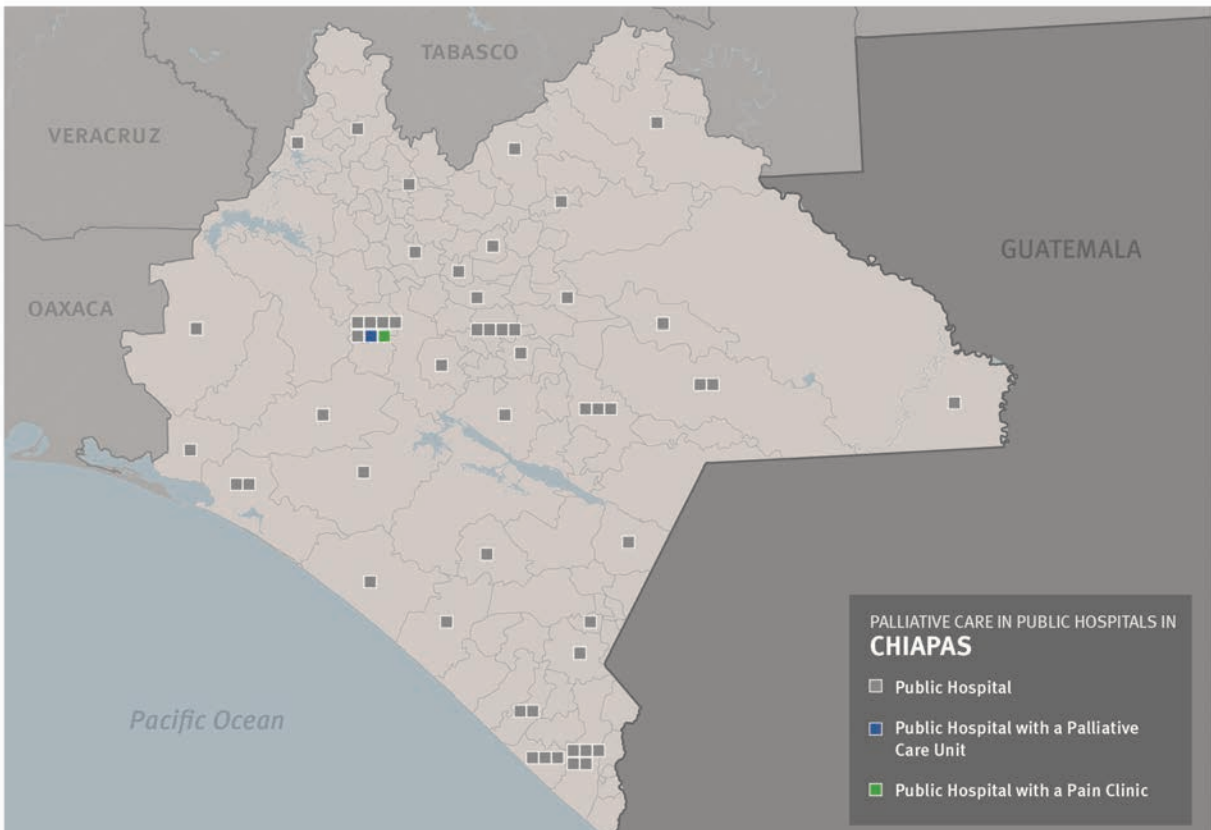
⁴⁴ Ibid.

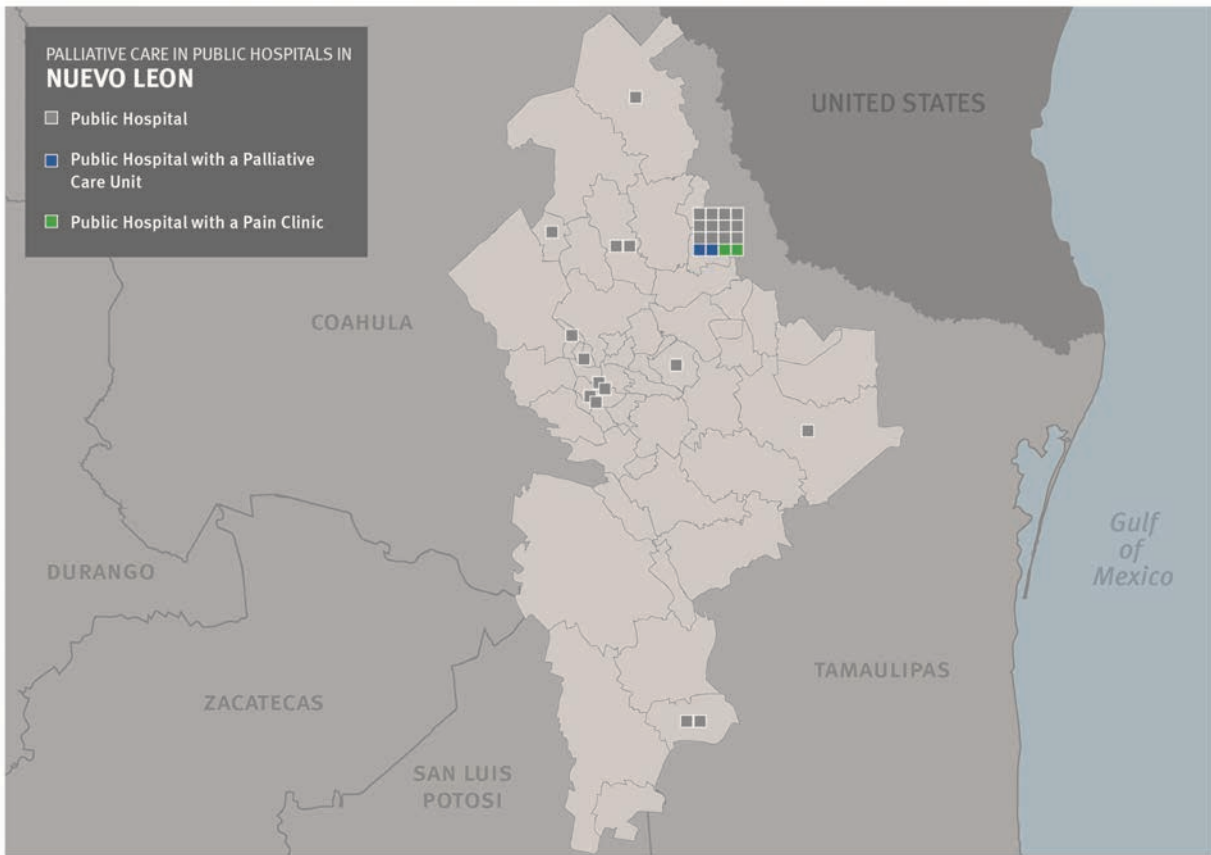
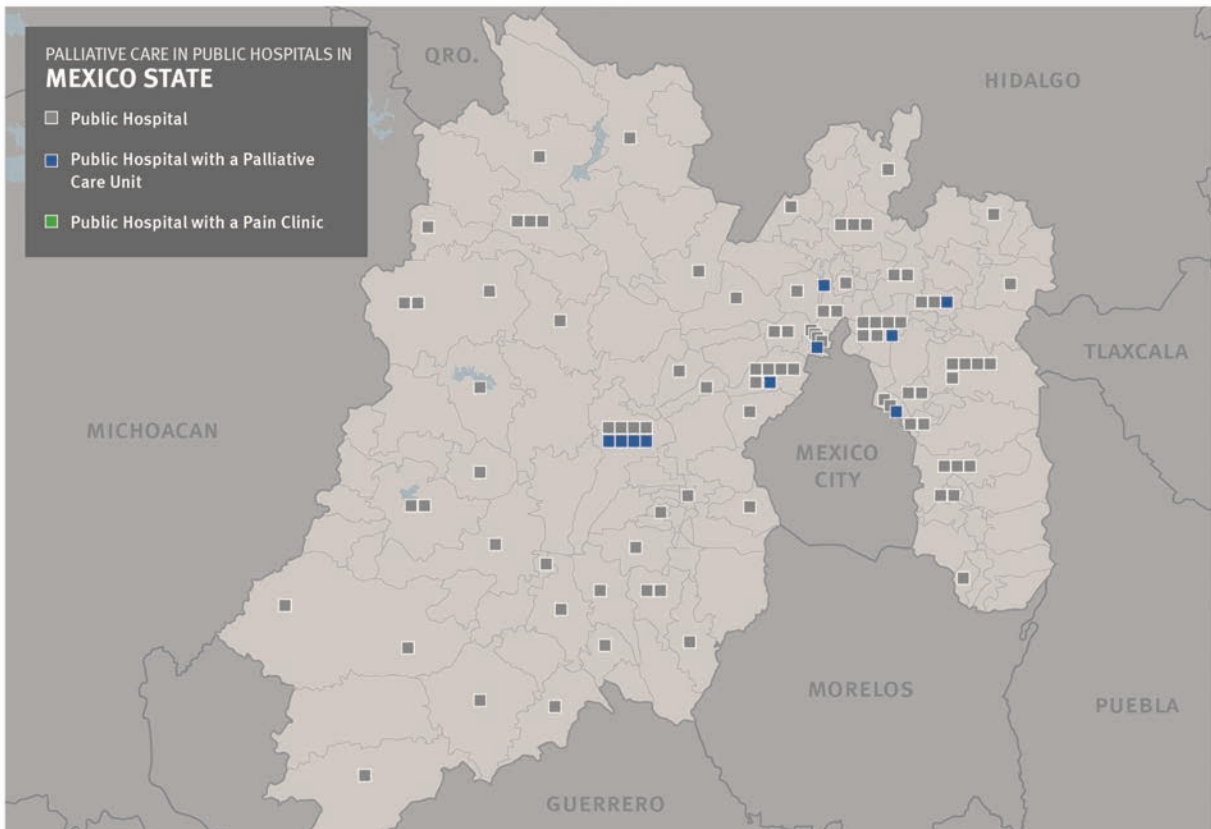
⁴⁵ Human Rights Watch interview with Liliana Arroyo (pseudonym), November 12, 2011, Guadalajara.

Outside Major Metropolitan Areas: Lack of Licensed Prescribers and Pharmacies

There is an alarming lack of doctors who obtain licenses to prescribe opioid analgesics and pharmacies that dispense them in much of Mexico. While in major cities, such as state capitals, there generally are some doctors with such licenses in pain clinics or palliative care units at major hospitals, outside the major cities it is often impossible to find doctors licensed to prescribe these medicines or pharmacies that dispense them. Patients who live there face the unenviable choice between traveling long distances to access treatment—often while in pain—or suffering without it. The reasons for the shortage of prescribers of these medicines, which are related to insufficient training of physicians in pain management and complicated bureaucratic requirements to be able to prescribe, are described in Chapter III.

As part of our research in the states of Chiapas, Jalisco, and Nuevo León we sought to identify all physicians who prescribe opioid analgesics to patients with chronic pain and all pharmacies that dispense these medicines. While there are multiple prescribers and pharmacies in the capital cities of all three states, there are almost none in the rest of these states. In Jalisco, for example, there are 14 municipalities with populations over 50,000 people. Just three of them have physicians who prescribe opioid analgesics for chronic pain and only one—Puerto Vallarta—also has a pharmacy that sells them. In Chiapas, two of the 22 municipalities with populations over 50,000 people outside of Tuxtla Gutiérrez—San Cristóbal de las Casas and Tapachula—have physicians that prescribe these medicines but only Tapachula has a pharmacy that sells them. None of Nuevo León’s three municipalities of more than 50,000 people outside the metropolitan area of Monterrey have physicians that prescribe opioids for chronic pain or pharmacies that sell the medicines. The state maps offer a visual representation of the situation in these states.





A publication by Raymundo Escutia, a pharmacist in Guadalajara, shows a similar dynamic in other states. His research found that in 2011 three states did not have a single pharmacy that sold oral morphine; in another 16 states, there were no such pharmacies outside the state capital.⁴⁶

As a result, people with pain from outside the major metropolitan areas often have to travel all the way to their state capitals in order to obtain or fill prescriptions for strong pain medicines. For many, such travel is an insurmountable barrier as they or their families either do not have the ability—financially or physically—to travel long distances or because their physicians do not refer them to colleagues able to prescribe opioid analgesics.

Dr. Araceli García Pérez, the only physician in Ciudad Guzman, Jalisco, who prescribes opioid analgesics for chronic pain, described the challenges for her patients as follows:

[Most of my] patients are unfortunately of low resources. Many have never been to Guadalajara. [It is a challenge for them] to find the Farmacias Especializadas where [morphine] is sold...Those with money...drive over to buy the medications but most patients have little means and a limited cultural level. For poor patients [it means] spending more money on the trip, without knowing Guadalajara...So it becomes something impossible for them to do.⁴⁷

She noted that these patients will pay more to travel to Guadalajara than for the medications.

Dr. Juan José Lastra, a general practitioner licensed to prescribe opioid analgesics, has a practice in Ajijic, a community outside Guadalajara with a large number of retired foreigners, mostly from the United States and Canada. He said:

If you tell the patient or the family: “Here’s the prescription, go and buy it,” the patient is going say that he needs it right now. They say: “It’s going to

⁴⁶ Raymundo Escutia et al., “Guía Practica del uso Racional de Analgésicos Opioides,” 2011, <http://www.ofil-internacional.org/uploads/documentos/Gu%C3%ADa%20pr%C3%A1ctica%20del%20uso%20Racional%20de%20Analg%C3%A9sicos%20Opioides%20Raymundo%20Escutia%20%202011.pdf> (accessed June 27, 2014).

⁴⁷ Human Rights Watch interview with Dr. Araceli García Pérez, November 13, 2011, Ciudad Guzman, Jalisco.

take me 1 hour to get to Guadalajara, half an hour in traffic, then back – it’s going to take me three hours.”⁴⁸

Dr. Carlos García, also a general practitioner in Ajijic said: “The majority of my patients are old. They mostly have serious health conditions, such as cancer. The patient generally can’t go so a family member has to make the trip.”⁴⁹

The lack of physicians that get licensed to prescribe opioid analgesics and the lack of pharmacies that sell them create a vicious cycle that perpetuates this untenable situation. Medical doctors do not prescribe opioid analgesics because of the hassle of obtaining prescription rights. Pharmacies do not stock the medicines because there are no physicians who prescribe them. This, in turn, becomes an additional disincentive for doctors to obtain prescription rights: Why should they do all the work to be able to prescribe these medicines when patients cannot fill the prescriptions locally anyway?

Accessing Pain Treatment in Urban Settings

While the situation in state capitals is significantly better than outside, there is a shortage of physicians licensed to prescribe opioid analgesics and pharmacies that sell them even there. In many places, only doctors at pain clinics at tertiary level hospitals have prescription rights, meaning people can only get these medicines if they are referred to those clinics. Furthermore, even in state capitals, the numbers of pharmacies that sell opioid analgesics is very low. In the metropolitan area of Guadalajara, a city of about five million people, just fifteen pharmacies stock these medicines.⁵⁰ In Tuxtla Gutiérrez, a city with a population of half a million people, just three pharmacies stock them.

This means that patients often have to travel significant distances within these cities in order to get to the doctors’ offices that prescribe these medicines and to pharmacies that can fill prescriptions. Sofía González, for example, a chronic pain patient in Guadalajara, told a Human Rights Watch researcher: “I have to go to a pharmacy that has controlled medicines...None of these pharmacies are nearby. I usually leave in the morning and have to take two buses. It takes two or three hours. Sometimes I can’t fill the prescription. I call

⁴⁸ Human Rights Watch interview with Dr. Juan José Lastra, November 11, 2011, Chapala, Jalisco.

⁴⁹ Human Rights Watch interview with Dr. Carlos García, November 11, 2011, Chapala, Jalisco.

⁵⁰ Email correspondence with Alan Ruiz, pharmacist at Instituto Palia in Guadalajara, June 27, 2014.

and they tell me whether they have it. Sometimes they don't...I try to talk to them before [my medicines] finish. When I have few drops left, I talk [to them]. I don't want to end up without..."⁵¹

Challenges Due to Strict Prescription and Dispensing Rules and Stock-Outs

Even when people are able to obtain a prescription for an opioid analgesic and access a pharmacy that sells these medicines, they may still face challenges getting their medicines: Mexico's inflexible regulations for prescriptions of opioid analgesics and unreliable supply often lead to pharmacies being unable to fill prescriptions for these medicines. Some doctors we interviewed estimated that pharmacies cannot fill up to 15 percent of their prescriptions for opioid analgesics (see below, Chapter III) because of current prescribing rules. For patients, the result can be being left without adequate pain medicines and spending hours traveling back to the doctor and then returning to the pharmacy.

For example, José Luis Ramírez, a man with a large throat tumor from Guadalajara, told a Human Rights Watch researcher that he had to return to the hospital when the pharmacy did not have the name of the medication indicated in the prescription, even though the same medication from a different pharmaceutical company was available:

There is one that is called Analfin [morphine] and they [only] have it with a different name. And because of that they don't give it to you. You have to go back to Palia [the hospital] so that they put it [the right name]. Otherwise they can't sell it to you.⁵²

A one-way trip to the hospital takes Ramírez an hour-and-a-half on public transport.

The brother of Esmeralda Márquez, an 82-year-old patient with chronic pain, said that on various occasions pharmacies could not fill prescriptions:

If you have a prescription for 15mg but they don't have them, they can't sell [other strengths]. I have to talk to the doctor and return to Palia [the

⁵¹ Human Rights Watch interview with Sofía González (pseudonym), November 15, 2011, Guadalajara.

⁵² Human Rights Watch interview with José Luis Ramírez (pseudonym), February 28, 2012, Guadalajara.

hospital] to get a new prescription. It's controlled [strictly]. I told her [my sister]: You know, it would be easier to buy marijuana.⁵³

Describing her desperation when her relatives were unable to fill her prescription, Daniela Moreno, a chronic pain patient in her eighties, said:

The day I don't have the tablet, I feel desperate...I feel in the night, oh, I can't sleep. The eight days that they couldn't find it...one day I put water in the bottle that had contained the tablets [and drank it] to see if it would stop the pain...It was desperation.⁵⁴

Reluctance to Prescribe Opioids: A Specialist's Task?

Throughout our research, both primary care physicians and oncologists interviewed repeatedly told us that they do not prescribe opioids because they see it as a pain specialist's job. These doctors often said they either prescribe weak pain medicines, sometimes even when pain is moderate to severe, or refer patients to a pain clinic.

Testimony from an oncologist who works in Tuxtla Gutiérrez and Tapachula in Chiapas was typical. The oncologist said that he had never sought a license to prescribe opioid analgesics even though he said it would not be hard to get. He said that he sends private patients to a palliative care expert in Tuxtla Gutiérrez and patients with pain at his public hospital in Tapachula to the pain clinic. The oncologist said that even though he routinely has patients with moderate to severe pain he does not have the "profile" to prescribe opioids and that he "prefers that they are managed by an expert."⁵⁵

Dr. Araceli García Pérez from Ciudad Guzman, the only physician licensed to prescribe opioid analgesics in her city of about 100,000 people, said:

Normally patients have to go to a pain doctor because general practitioners are not trained for this kind of situation. They therefore prefer not to get involved in this stuff. It is a pain having to ask for prescription forms

⁵³ Human Rights Watch interview with Esmeralda and Miguel Márquez (pseudonyms), November 12, 2011, Guadalajara.

⁵⁴ Human Rights Watch interview with Daniela Moreno (pseudonym), November 10, 2011, Guadalajara.

⁵⁵ Human Rights Watch interview with José Escobar (pseudonym), April 25, 2012, Tuxtla-Gutiérrez, Chiapas.

etcetera when you don't really know how to manage these things [prescribing of opioids].⁵⁶

For patients, however, this often means adding extra steps, requesting additional appointments with the pain clinic and making extra trips to the hospital. It also appears to result in the overprescribing of weak pain medicines by physicians who do not prescribe opioids but delay referring their patients to pain or palliative care specialists. A number of palliative care or pain physicians complained that their colleagues' lack of knowledge about pain management led to the excessive use of over-the-counter pain medicines which, when used over extended periods of time, can do serious and irreversible damage to the gastrointestinal tract and the kidneys. Dr. Jesús Medina, a physician at Instituto Paliá, described a situation he and his colleagues commonly see:

Patients come in very advanced stages. They've been on non-opioids pain medicines for years. The doctors have already screwed up their stomachs. They already have renal problems due to high use of non-steroidal anti-inflammatory drugs (NSAIDs)...The NSAIDs are much more dangerous than the opioids. Side effects of narcotics can be managed. We have geriatric patients who have been using NSAIDs daily for 11 to 14 months. Of course they already have intense gastrointestinal problems. They are nutritionally compromised as they are not eating because it hurts to eat.⁵⁷

Dr. Araceli García Pérez from Ciudad Guzman concurred:

Sometimes surgeons, gynecologists, oncologists have patients who are terminal that should be in palliative care...Oncologists don't know how to treat patients with pain. I've seen patients [in moderate to severe pain] that they [the oncologists] continue to give paracetamol, paracetamol and paracetamol. I tell them why? They say it's the only thing. The patients are already almost in death throes...and they still continue to give them paracetamol. They [the doctors] panic at the thought of morphine.⁵⁸

⁵⁶ Human Rights Watch interview with Dr. Araceli García Pérez, November 11, 2011, Ciudad Guzman, Jalisco.

⁵⁷ Human Rights Watch interview with Dr. Jesús Medina, November 16, 2011, Guadalajara.

⁵⁸ Human Rights Watch interview with Dr. Araceli García Pérez, November 13, 2011, Ciudad Guzman, Jalisco.

A patient who was receiving 50 mg of morphine per day told us that her oncologist recommended that she immediately stop taking morphine after she had a colectomy.⁵⁹ The oncologist apparently did not realize that this would have caused her patient to go into withdrawal. Luckily for the patient, she consulted her doctor at Instituto Palia before following the oncologist's recommendation. Dr. Jesús Medina, the physician who treated her at Instituto Palia, told Human Rights Watch he encounters stories like that on a regular basis.⁶⁰

Access to Palliative Care for Children

Antonio Méndez's Story

Antonio Méndez, the youngest child in a middle-class family in Tepatitlán de Morelos, a town of about 100,000 inhabitants in the state of Jalisco, was almost six when his parents noticed that he had a significantly swollen ganglion in his neck in 2008.⁶¹ Thinking it was an ordinary infection, a local doctor prescribed antibiotics. However, neither this nor a second course of antibiotics succeeded in bringing down the swelling. Although Antonio was eating well, his parents said that he also inexplicably began to lose weight. Concerned about his health, they took him to a hospital in Guadalajara for a biopsy. The results came back positive for a rare form of cancer called rhabdomyosarcoma, a malignant tumor of the muscles.

When Human Rights Watch researchers visited him in February 2012, Antonio was nine and had been receiving chemo and radiation therapy for three-and-a-half years at a hospital in Guadalajara, about 50 miles from his home. His prognosis was bleak: he had metastases in his head and in his lungs. At the time, Antonio had a visible tumor in his neck and his eye had recently become swollen as well. We decided not to interview him because he was experiencing significant discomfort, but we spoke to his parents.

Antonio's parents knew that their son's cancer had become incurable and they were ready to accept the fact that he was going to die. They had grown increasingly wary about continuing with chemotherapy and the impact its side effects had on Antonio. As his mother told us:

⁵⁹ Human Rights Watch interview with Beatriz Álvaro (pseudonym), November 15, 2011, Guadalajara.

⁶⁰ Human Rights Watch interview with Dr. Jesús Medina, November 16, 2011, Guadalajara.

⁶¹ Human Rights Watch interview with the parents of Antonio Méndez (pseudonym), February 24, 2012, Tepatitlán, Jalisco.

Antonio has been getting chemo for three years. [He had] only a single three month [break] because he was getting radiation therapy...[T]he consequences of the chemo have been many: hemorrhage, constipation, nausea, throwing up everything, low immune system, low platelet count, meningitis infection...This month, the chemo burnt a little vein here. The chemo has so many consequences...

While the family was ready to embrace treatment focused on Antonio's quality of life rather than on cure, the hospital did not have a palliative care unit or staff trained in palliative care. None of the doctors at the hospital had discussed the option of palliative care with them despite the fact that Antonio was a likely candidate for palliation and that Guadalajara, where he was receiving treatment, has multiple hospitals that offer palliative care, including for children. Instead of offering palliative care, Antonio's oncologist convinced his parents to continue with more chemotherapy. Antonio's mother told us:

When I was told a year ago that the cancer had infiltrated, I said: "We're not going to give him any more chemo." But the doctor said: "If you don't give him chemo, it [death] is going to happen sooner."

Given no other option, Antonio's parents agreed to continue with chemotherapy despite their misgivings.

When we met with them, Antonio's parents had no idea what palliative care was, even though it coincided almost exactly with the wishes they had for their son's care. Unfortunately, they said, it was very difficult to discuss their priorities for their son's care with the oncologist. Although Antonio's mother thought the doctor was very competent, she was not willing to engage in discussions of their son's care. His mother said:

Antonio's oncologist is of few words. She gives you the diagnosis but she never explains anything. Never, ever. And she doesn't like you asking. If you keep asking, she stops you, kind of "that's enough."

Antonio's father added: "Don't even ask because she's very sensitive."

In December 2011, Antonio developed severe pain. His mother said that he would cry a lot and grab his head. The oncologist referred him to the hospital's pain clinic where a doctor prescribed morphine. However, the doctor had instructed Antonio's parents to give him a quarter tablet of morphine in the morning and another in the evening. If he suffered from a lot of pain the doctor told them to give him three or four doses per day. These instructions were inconsistent with recommendations from the WHO on cancer pain treatment, which stipulate that patients should receive morphine every four hours to ensure continuous pain relief.⁶² As a result, Antonio continued to be in pain during much of the day. Eventually, his mother decided herself to start giving him morphine every four hours when he was in a lot of pain.

The doctors at the pain clinic also failed to provide Antonio's parents with adequate information on the side effects of morphine. His mother said that they "have never really talked to me about it or anything." As a result, Antonio suffered from constipation and nausea without appropriate treatment. She said:

When I gave it [morphine] to him for the first time...his stomach would hurt 20 minutes later. What is the point on of taking pain away from him if we cause another [symptom]...?" We had to go all the way [to Guadalajara] to ask.

Antonio's mother also said she was concerned—unnecessarily—that if her son received morphine now it might stop working when his pain would get even worse: "I told myself: 'Well, I'll give it to him more often,' but at the same time I thought: 'If I give it to him more often, when he experiences this strong pain it's not going to work on him.'"

Their son's illness had created enormous stress and anxiety within the family, something that a palliative care team could have helped resolve. Antonio's mother, for example, described a near breakdown she had suffered a week before our visit in February 2012:

Last week I felt so bad when I saw Antonio's eye [swollen] like that. I have lived through the disease with Antonio for three years...and he has been severely ill... Still, [it was the first time] that I said: "No, it's my husband's

⁶² WHO, "WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses," 2012, http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf, p. 48-49. (accessed on July 14, 2014).

turn now, I don't want to see anymore." And at the same time I said: "What if my son sees that his mother isn't present anymore," so then I stayed. But yes, emotionally I was about to quit last week.

Weighing most heavily on Antonio's parents was the lack of information about what was going to come as their son deteriorated and about how they should care for him. They were in charge of caring for a child who was dying and nobody had told them or him what to expect and how to manage. When Human Rights Watch staff offered to put the family in touch with a pediatrician in Guadalajara who was specialized in pediatric palliative care, one of Antonio's mother's first questions was: "His oncologist, she hasn't talked to me honestly about what can happen. Can she [the palliative care physician] talk to me openly about that?"

The pediatric palliative care physician, Dr. Yuriko Nakashima, cared for Antonio during his last few months, controlling his pain and other symptoms and assisting him and his parents between home visits by phone and video. Antonio eventually died peacefully in May 2012.

The Lack of Palliative Care Services for Children

The WHO defines children's palliative care as "the active total care of the child's body, mind and spirit," as well as support for the family.⁶³ Children's palliative care includes efforts to assess and treat pain; the provision of medicines in appropriate formulations for children; support for the child through play, education, counseling and other methods; child-appropriate communication about the illness; and communication with, and support for, the family.⁶⁴ It should also address child protection, as some severely ill children are vulnerable to exploitation, abuse and neglect.⁶⁵ Hence, palliative care for children requires pediatric expertise, including on child-specific symptoms and diseases, as well as expertise in child psychology and child protection.

⁶³ WHO, *National Cancer Control Programs: Policies and Managerial Guidelines*, 2002, p. 85, <http://www.who.int/cancer/media/en/408.pdf> (accessed February 12, 2010). See also Justin Amery, ed., *Children's Palliative Care in Africa* (New York: Oxford University Press, 2009).

⁶⁴ WHO, *National Cancer Control Programs: Policies and Managerial Guidelines*, <http://www.who.int/cancer/media/en/408.pdf>, p. 85. See also Amery, *Children's Palliative Care in Africa*.

⁶⁵ Amery et al., "The Beginning of Children's Palliative Care in Africa," *Journal of Palliative Medicine* 12 (2009): 1015-21, accessed June 27, 2014, doi: 10.1089/jpm.2009.0125.

Palliative care is very important for children with life-limiting illness. For children, serious illness, pain, hospitalization, and invasive medical procedures are often profoundly disorienting and traumatizing and can cause great suffering. For parents and caregivers, watching a child suffer from symptoms and medical procedures, balancing the needs of the sick child with those of other children, and facing the prospect of potentially the child's death, cause great distress. Pediatric palliative care can help both children and parents navigate these difficult circumstances by relieving distressing physical symptoms, minimizing pain due to medical procedures, and enhancing communication among health care workers, children and parents about the child's illness and prognosis.

Thousands of children in Mexico need palliative care annually, including more than 1500 children who die of cancer each year. Doctors at the palliative care unit of the National Pediatrics Institute (NPI) in Mexico City, the largest children's hospital in the country, estimate that about 40 percent of all children attended at this tertiary care hospital have life-limiting illnesses and potentially require palliative care.⁶⁶ A study of more than a thousand children attended by the palliative care unit of the NPI found that about 38 percent of patients had cancer; almost 30 percent had severe neurological conditions, such as epilepsy, encephalopathy, and hydrocephaly; and the rest a variety of other conditions.⁶⁷ A review of symptoms of a sample of these patients showed that 70 percent suffered from bronchial or oropharyngeal secretions (wet secretions from the mouth or throat that cause an unpleasant rattling sound) and 67 percent suffered from pain.⁶⁸

As with adults, very few hospitals offer pediatric palliative care, meaning that this health service is inaccessible to many families who require it. Children are even worse off as only six hospitals in all of Mexico—the National Pediatric Institute, Hospital General Dr. Manuel Gea González in Mexico City, the Hospital Civil de Guadalajara, Hospital del Niño in Toluca, Hospital del Niño in Morelos and Hospital Infantil Teletón de Oncología, a charitable hospital—are known to have specialized pediatric palliative care teams. The remainder of the more than forty hospitals in Mexico that attend to children with cancer and other advanced diseases do not have known palliative care services.

⁶⁶ Garduño et al, "Cuidados Paliativos en Pediatría. Experiencia en 1121 Niños del Instituto Nacional de Pediatría de México," Draft article. On file with Human Rights Watch.

⁶⁷ Ibid.

⁶⁸ Ibid.

The pediatric specialty hospital in Tuxtla Gutiérrez, Hospital de Especialidades Pediátricas, is one example. This hospital, which opened in 2006, offers comprehensive secondary level health services for children in Chiapas, including treatment for cancer and other life-limiting illnesses. It is the only such hospital in the state. The hospital's oncology department sees about 60 children with cancer per year.⁶⁹ According to oncologists at the hospital, only about 20 percent of these children survive.⁷⁰

Yet, the hospital does not have a palliative care unit, anyone on staff with palliative care training, or any physician licensed to prescribe strong opioid medicines for chronic pain. Children who become incurable are sent home and told to come back every two weeks for follow-up appointments. Patients who require pain management are sent to the regional hospital, which has a pain clinic but no staff trained specifically in pediatric pain management. The hospital has no call service to support parents of children who are dying at home. When a child has complications or a spike in pain they have no other option but to go to the emergency room of the hospital. For many patients, however, this trip can take many hours.

Oncologists at the hospital lamented not being able to offer palliative care. One told Human Rights Watch:

I think palliative care is very important because many patients feel that you are not going to attend to their needs anymore, that you are abandoning them. If we had palliative medicines, we could continue to have support of the hospital.⁷¹

⁶⁹ Interview with director and oncologists at Hospital de Especialidades Pediátricas, Tuxtla Gutiérrez, Chiapas, April 23, 2012.

⁷⁰ Ibid.

⁷¹ Ibid.

Two Pediatric Palliative Care Models: Morelos and Mexico State

The experiences of two public children's hospitals in central Mexico we visited demonstrate how a relatively limited investment in palliative care, paired with strong leadership, can achieve significant results in improving the care for children with incurable or terminal illness. The two hospitals—the Hospital del Niño in Toluca, Mexico State and the Hospital del Niño in Cuernavaca, Morelos—each set up palliative care programs in 2013.⁷²

Both hospitals use broadly similar models to provide palliative care. Each has at least one full-time staff member dedicated exclusively to palliative care that coordinates the care of patients. Both hospitals have home-based care services and offer round-the-clock support to patients and parents via telephone and/or text message. The administrations of both hospitals have also designated physical space—in Cuernavaca, a procedure room, in Toluca, a small office—to the palliative care service.

In both hospitals, the decision to refer a child to palliative care is taken by the treating physician, usually when curative treatment is discontinued. Following such referral, the physician works with the multidisciplinary palliative care team to develop a care plan for the patient; a meeting is held with the family to discuss the child's prognosis and the options for care; the family is trained in the provision of basic care at home and provided emergency contact information for the palliative care services; and ultimately, in most cases, the child goes home where he or she receives regular visits from members of the palliative care team.

In Toluca, by June 2014, the palliative care service had cared for 138 children with terminal or incurable illnesses since it began operating in February 2013. At the time of the visit, 59 of these patients had passed away, more than half in their homes. In its first year, the palliative care service in Cuernavaca had cared for 58 children. Three quarters of the forty-five who had passed away did so in their homes.

⁷² This text box is based on visits to the Hospital del Niño in Toluca on June 16, 2014 and to Hospital del Niño in Cuernavaca on June 18, 2014.

The directors and staff at both hospitals said that feedback from patients and their families on the palliative care service had been very positive. Furthermore, they also noted that hospital stays for these children were often shorter than before, potentially leading to cost savings for the hospital. They said this was particularly true for children who require round-the-clock ventilators due to severe neurological or congenital malformations. Previously, many of these children had no option but to stay in the hospital for extended periods of time whereas the palliative care services have allowed many of them to obtain these services at home.

Both hospitals also reported challenges. The palliative care teams said that in the beginning, they had encountered significant resistance on the part of some physicians who did not want to refer their child patients to palliative care. They said that over time they had overcome much of this reluctance through training and direct experiences. Many physicians now recognize the benefits of palliative care for their young patients. However, the hospitals cited lack of adequate staff and insurance coverage for palliative care and difficulties prescribing opioid medicines as challenges.

III. Exploring the Causes for the Palliative Care Gap

The WHO and its decision-making body, the World Health Assembly (WHA), recommend the integration of palliative care into national health systems. To achieve this, the WHO recommends that governments formulate and implement a number of specific policies that it considers essential for expanding palliative care, including:

- Health system policies to ensure the integration of palliative care into the structure and financing of national health care systems at all levels of care;
- Policies for strengthening and expanding human resources, including education and training of health care professionals, in order to ensure adequate responses to the palliative care needs, together with training of volunteers and education of the public;
- A medicines policy in order to ensure the availability of essential medicines for the management of symptoms, including pain and psychological distress, and in particular, opioid analgesics for relief of pain and respiratory distress;
- A policy for research into assessing the needs for palliative care and identifying standards and models of service that work, particularly in limited resource settings.⁷³

A World Health Assembly resolution on palliative care adopted on May 23, 2014, which Mexico co-sponsored, closely mirrors these recommendations.⁷⁴

These recommendations also correspond closely with several obligations under the right to health. The Committee on Economic, Social and Cultural Rights, the body that monitors the implementation of the right to health as articulated in the International Covenant on Economic, Social and Cultural Rights (ICESCR),⁷⁵ has held that countries must adopt and

⁷³ WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf.

⁷⁴ WHA resolution 67.19, Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course, May 14, 2014, http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (accessed June 26, 2014).

⁷⁵ International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force January 3, 1976, art. 12; also in the Convention on the Rights of the Child (CRC), G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, art. 12.

implement a national public health strategy and plan of action and ensure access to essential medicines as defined by the WHO.⁷⁶ It has identified providing appropriate training for health personnel as an obligation “of comparable priority.”⁷⁷ Failure to take steps in these three areas may result in a violation of the right to health.

Integration of Palliative Care into the Healthcare System

According to the WHO, national health system policies should promote the integration of palliative care into the structure and financing of national health care systems at all levels of care. In these policies, the emphasis should be on primary care, community and home-based care.⁷⁸ The WHO also recommends that palliative care be part of efforts to promote universal health coverage.

The right to health requires states to take the steps necessary for the “creation of conditions which would assure **to all** medical service and medical attention in the event of sickness” (emphasis added).⁷⁹ The Committee on Economic, Social and Cultural Rights has held that people are entitled to a “system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.”⁸⁰ In other words, health services should be available for all health conditions, including chronic or terminal illness, on an equitable basis.

The 2009 palliative care amendments to Mexico’s health law are closely in line with these WHO recommendations and human rights obligations. The amendments explicitly oblige all healthcare institutions to offer palliative care services, including counseling about illness, treatment of pain and psychological support. This is only possible with the integration of palliative care into the structure and financing of the healthcare system. A

⁷⁶ UN Committee on Economic, Social and Cultural Rights, “Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights,” General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (2000), [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358boe2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358boe2c1256915005090be?Opendocument) (accessed May 11, 2006), para. 43.

⁷⁷ *Ibid.*, para 44(f).

⁷⁸ WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf, p 20(i).

⁷⁹ ICESCR, art. 12 (2).

⁸⁰ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para 8.

February 2013 meeting on the role of palliative care in Mexico's national cancer strategy clearly identified this as a priority.⁸¹

As noted, however, implementation has lagged as the ministry of health has yet to adopt the implementing norm for the amendments. As a result the actual integration of palliative care into the structure of the healthcare system at all levels of care has not happened to date. Mexico has made some significant advances at the tertiary level of care where a growing number of hospitals are now offering palliative care as a core part of their health services. But at secondary and primary care levels palliative care is still mostly non-existent.

Integration of Palliative Care into Health Insurance Schemes

With most of its population covered by a health insurance scheme, Mexico has the infrastructure to deliver palliative care to most people who need it. However, the availability of palliative care services among providers in the networks of these insurers is very limited and one major health insurer only covers palliative care partially for most patients.

⁸¹ Silvia Allende-Pérez, Emma Verástegui-Avilésb, Alejandro Mohar-Betancourt, et al., "Incorporación de los cuidados paliativos al Plan Nacional de Cáncer: consenso," *Gaceta Mexicana de Oncología* 12 (2013):213-222, accessed June 27, 2014, http://www.imbiomed.com.mx/1/1/articulos.php?method=showDetail&id_articulo=99984&id_seccion=2290&id_ejemplar=9742&id_revista=139.



Seguro Popular

Prior to 2014, Seguro Popular did not cover palliative care for many conditions, including many cancers. The 2012 list of basic medical interventions and medicines, the Universal Catalogue of Health Services, that are covered under the insurance, for example, did not include a specific intervention for palliative care or include a number of key symptoms that many palliative care patients face, such as pain and breathlessness.⁸² This meant that the several dozen public hospitals that attend to Seguro Popular patients and that do have palliative care available had to charge them for such services or had to provide them free-of-charge without possibility of being reimbursed.

To address this gap in coverage, the National Commission for Social Protection of Health (NCSPH), which administers Seguro Popular, added an intervention entitled “Attention for certain signs, symptoms, and other factors that influence the state of health” to the 2014

⁸² Seguro Popular, “Catálogo Universal de Servicios de Salud,” 2012, <http://www.seguropopularoaxaca.gob.mx/documentos/CAUSES2012.pdf> (accessed June 27, 2014).

catalogue which includes various common symptoms in palliative care patients, including pain and breathlessness.⁸³ Each intervention in the catalogue comes with a list of recommended medicines. Yet, curiously, the list of medicines for the intervention on control of symptoms does not include any opioid pain medicines, even though injectable morphine, tramadol, and buprenorphine were added to Seguro Popular's general medicines list.⁸⁴ While physicians can prescribe any of the medicines on Seguro Popular's list for any covered condition, the lack of inclusion of key pain medicines with the intervention on symptom control may well discourage physicians from using them. The NCSPPH is currently reviewing the financial feasibility of adding coverage of a more comprehensive set of palliative care interventions in the future.⁸⁵

The Fund for the Protection against Catastrophic Costs (Fondo de Protección contra Gastos Catastróficos), which covers certain complex medical conditions that generally involve major expenditure for treatment, including all pediatric cancers, some adult cancers and HIV, also does not cover palliative care adequately.⁸⁶ While the Fund covers diagnostic tests and curative treatment for these illnesses, the Fund's documentation is not explicit on whether its beneficiaries are entitled to receive palliative care.⁸⁷ The Fund's essential medicines list does include various strong opioid analgesics.⁸⁸

⁸³ See intervention no. 88 in the Universal Catalogue of Health Services (Catálogo Universal de Servicios de Salud) of March 2014. The other symptoms covered include, among others: palpitations, bleeding from the nose, cough, hyperventilation, nausea, vomiting, skin conditions, flatulence, involuntary movements, fainting, and fatigue. On file with Human Rights Watch.

⁸⁴ Ibid.

⁸⁵ Email correspondence with Celina Castañeda of the National Commission for Social Protection in Health, September 12, 2014.

⁸⁶ "Intervenciones Del Fondo De Protección Contra Gastos Catastróficos 2012," undated, <http://www.saludzac.gob.mx/site/images/stories/SeguroPopular/FormatosPDF/1intervencionesfpcgc2012.pdf> (accessed June 27, 2014).

⁸⁷ Ibid.

⁸⁸ Published in the Diario Oficial de la Federación on November 30, 2012. Available at: http://www.dof.gob.mx/nota_detalle.php?codigo=5281003&fecha=30/11/2012 (accessed June 27, 2014).



Mexican Social Security Institute (IMSS)

IMSS will cover palliative care interventions and medicines.⁸⁹ However, few IMSS hospitals and clinics actually offer palliative care services. We identified just three tertiary care hospitals within the IMSS system—in Mexico City, Monterrey, and Cuernavaca—that offer palliative care and none at the secondary level.⁹⁰ Thus, although palliative care in theory is covered for patients with IMSS, most cannot actually access it because of its limited availability. IMSS’ medicines list includes most essential palliative care medicines that are available in Mexico (see below under Medicines Availability), although not all are available at primary and secondary levels of care.

⁸⁹ IMSS does not have a published list of interventions that are covered. However, IMSS officials informed us that in principle all palliative care interventions an IMSS-associated physician deems necessary are covered. Meeting with Javier Dávila, director of medical services, Pedro Escudero, director of Hospital de Oncología of the National Medical Center Siglo XXI, Víctor Borja, director of the unit for primary health care, and Manuel Cervantes, coordinator of integral primary health care, June 18, 2014, México City, organized by Fundación Mexicana para la Salud and Tómatelo a Pecho.

⁹⁰ Another eleven IMSS hospitals have pain clinics.

IMSS has a home-based care program for people with chronic illnesses at 140 of its general and specialist hospitals, which attended to 35 thousand patients in 2013 and could be a good vehicle for delivering palliative care.⁹¹ However, at present the program is designed for patients with long-term care needs rather than for those with a prognosis of short-term survival and health needs that require immediate assistance. The program has limited capacity which means that patients with advanced illness cannot always enroll immediately. Furthermore, staff of these home-based care programs are not currently trained in the provision of palliative care.

IMSS boasts an award winning palliative care service in Monterrey, Nuevo León, that serves several states in northeastern Mexico.⁹² This service, which operates out of Unidad Medica de Alta Especialidad 25 (UMAЕ 25), uses a decentralized model to assist patients. The service has invested extensively in training primary care physicians in the northeastern region and refers patients to primary care givers for day-to-day care. For prescriptions for opioid analgesics and more complex symptom management patients do still need to travel to Monterrey but the cooperation with primary care givers has reduced the need for patients to travel back-and-forth. The director of UMAЕ 25 credits the palliative care service with a significant reduction of bed occupancy in the hospital's oncology unit.⁹³

⁹¹ The program is called ADEC (Atención domiciliaria al enfermo crónico). Data received from IMSS, communication of October 13, 2014. <http://www.cronica.com.mx/notas/2008/352686.html> (accessed October 3, 2014).

⁹² In 2009, the palliative care service was an award for innovation in the quality of healthcare. Human Rights Watch interview with Dr. José Alberto Flores Cantisani, Monterrey, Nuevo León, October 8, 2013.

⁹³ Human Rights Watch interview with Dr. Pablo Moreno, Monterrey, Nuevo León, October 8, 2013.



Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (ISSSTE)

ISSSTE does not appear to have a public list of the medical conditions and interventions it covers or a public medicines list. However, key informant interviews suggest that palliative care interventions, such as management of physical and psychosocial symptoms, are covered when available. We identified five of a total of 110 ISSSTE hospitals—in Chiapas, Chihuahua, Mexico City, Guanajuato and Puebla—that have palliative care services.⁹⁴

Lack of Referral Systems

The WHO and the WHA resolution recommend that people who require palliative care can receive it in their home or community. International human rights standards hold that health services should be within “safe physical reach for all sections of the population, especially vulnerable and marginalized groups.”⁹⁵ This is only possible with the existence

⁹⁴ We also identified eleven ISSSTE hospitals that have pain clinics. ISSSTE hospitals were identified through the health ministry’s website: <http://plataforma.salud.gob.mx:8091/> (accessed September 29, 2014).

⁹⁵ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, para 12b.

of palliative care capacity at the primary care level, which is sorely lacking in Mexico. It also requires a functioning referral system so that patients who become incurable are referred back to healthcare providers in or close to their communities.

As testimony from people with life-limiting illnesses and their families above shows clearly, such a system does not currently exist in Mexico even when community or home-based palliative care services are available. Palliative care services and their capacities are currently not recorded or circulated in any way, complicating referrals. For example, organograms of Mexico's hospitals do not include palliative care services or pain clinics.

Some hospitals have set up their own referral systems. For example, through its extensive training activities, the palliative care unit of Instituto Nacional de Ciencias Médicas y Nutrición Salvador Zubirán in Mexico City has built up a network of trained physicians in many parts of the country that it refers patients to when they finish their hospital treatment so that they no longer have to travel to Mexico City to receive palliative care services.⁹⁶ The National Cancer Institute works with a network of cancer centers that includes 33 hospitals around the country, 18 of which have palliative care units, although three of the states where most of their patients come from, Hidalgo, Morelos, and Tlaxcala, do not have regional cancer centers.⁹⁷ UMAE 25 of IMSS in Monterrey has developed its own referral system to primary physicians in Nuevo León and adjacent states by investing in training of primary care physicians in palliative care. When patients are ready to be sent home, the hospital draws up referral instructions for primary physicians so that they can offer services to patients close to their homes.⁹⁸

Palliative Care Education for Healthcare Workers

Adequate training and education for healthcare workers in palliative care is essential to the rollout of this health service. As noted above, the Committee on Economic, Social and Cultural Rights considers appropriate training of healthcare workers an obligation of key importance.⁹⁹ Accordingly, the WHO recommends that “education about palliative care

⁹⁶ Human Rights Watch interview with Dr. Argelia Lara, September 20, 2011, México City.

⁹⁷ Email correspondence with Dr. Emma Verástegui, July 10, 2014.

⁹⁸ Human Rights Watch interview with Dr. José Alberto Flores Cantisani, Monterrey, Nuevo León, October 8, 2013.

⁹⁹ UN Committee on Economic, Social and Cultural Rights, “Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights,” General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (2000),

(including ethical aspects) is offered to students in undergraduate medical and nursing schools and to health care providers at all levels...”¹⁰⁰ The May 2014 World Health Assembly resolution calls on countries to include palliative care as an “integral component of the ongoing education and training offered to care providers” and specifies:

(a) basic training and continuing education on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level, including health care workers, caregivers addressing patients’ spiritual needs and social workers;

(b) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics and internal medicine;

(c) specialist palliative care training should be available to prepare health care professionals who will manage integrated care for patients with more than routine symptom management needs.¹⁰¹

To date, palliative care has not yet been integrated into curricula and continuing education programs for healthcare workers. Mexico City and Guadalajara each have multiple training programs for different kinds of healthcare workers and at different levels but in the rest of the country such programs are almost entirely non-existent. As a result, most healthcare workers in Mexico have no knowledge of palliative care and lack any clinical exposure to this health service, greatly complicating efforts to integrate palliative care into the healthcare system.

Research by the Latin American Palliative Care Association (ALCP) on palliative care in Mexico demonstrates the extent of the training capacity gap (see Table 2).¹⁰² It found that

[http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358boe2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358boe2c1256915005090be?Opendocument) (accessed May 11, 2006), para 44(f).

¹⁰⁰ WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf.

¹⁰¹ WHA resolution 67.19, Strengthening of Palliative Care as a Component of Comprehensive Care throughout the Life Course, http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf.

just six medical schools in Mexico teach palliative care as part of the curriculum and that it is mandatory in just two.¹⁰³ Mexico has a total of 102 medical schools.¹⁰⁴ A recent publication in the journal *Palliative Medicine* found that Mexico ranked 12th of 19 countries in the region in integration of palliative care into undergraduate medical curricula.¹⁰⁵ According to the report, the Asociación Mexicana de Facultades y Escuelas de Medicina, which is made up of 54 medical schools and makes non-binding recommendations about medical curricula, plans to include palliative care into its model curricula.¹⁰⁶ Mexico's universities enjoy wide discretion in setting curricula for their academic programs, complicating any potential efforts by the government to ensure palliative care is taught in medical schools and other relevant university courses.

According to the ALCP study, just four nursing schools, three faculties of psychology, and two faculties of social work include palliative care as part of their curricula. The report identified forty-five medical doctors who teach palliative care and 25 non-medical palliative care trainers. It said about 250 medical doctors had completed palliative care courses.

The ALCP study did not seek to identify to what extent palliative care is integrated into continuing education programs for medical doctors, nursing staff, psychologists, pharmacists and social workers. The need for such programs is enormous as most existing healthcare workers have not had any training or clinical exposure to palliative care.

To date, there have not been any concerted efforts by the government, the healthcare system or academic institutions to systematically incorporate palliative care into training curricula and programs for healthcare workers. This may change now that the health

¹⁰² Asociación Latinoamericana de Cuidados Paliativos, "Atlas de Cuidados Paliativos de Latinoamérica, Edición cartográfica," 2013, <http://cuidadospaliativos.org/uploads/2014/3/Atlas%20Latinoamerica%20-%20edicion%20cartografica.pdf>, pp. 46, 47.

¹⁰³ The Atlas states that five medical schools have included palliative care into the undergraduate curriculum. However, the authors have informed us of a sixth medical school. Communication with Tania Pastrana of ALCP, April 14, 2014.

¹⁰⁴ Presentation by Giota Panopoupou, department of integration and development in the health sector, Ministry of Health at the Second International Forum "Toward Effective Universality of the Health System: Access to Palliative Care and Pain Control," October 13, 2014.

¹⁰⁵ Tania Pastrana, Isabel Torres-Vigil, and Liliana De Lima, "Palliative care development in Latin America: An analysis using macro indicators, *Palliative Medicine*," 2014, <http://pmj.sagepub.com/content/early/2014/06/12/0269216314538893.full.pdf?ikey=czz8VDFCw7mw3ce&keytype=ref> (accessed July 15, 2014).

¹⁰⁶ Asociación Latinoamericana de Cuidados Paliativos, "Atlas de Cuidados Paliativos de Latinoamérica, Edición cartográfica," <http://cuidadospaliativos.org/uploads/2014/3/Atlas%20Latinoamerica%20-%20edicion%20cartografica.pdf>, p 47.

ministry has hired a palliative care physician with extensive training experience to help it develop its work plan in this area.

Table 2 – Palliative Care Education¹⁰⁷

	Medical schools	Nursing schools	Psychology	Social work
Undergraduate	<ul style="list-style-type: none"> - Universidad Autónoma de Guadalajara (mandatory) - Universidad de Guadalajara (mandatory) - Universidad Panamericana (elective) - Universidad Nacional Autónoma de Mexico (UNAM) (elective) - Universidad La Salle (elective) - Instituto Politécnico Nacional (elective) 	<ul style="list-style-type: none"> - Universidad de Guadalajara (mandatory).* 	<ul style="list-style-type: none"> - Universidad Autónoma de Guadalajara (elective) - Universidad Jesuita de Guadalajara (ITESO) (mandatory)* 	<ul style="list-style-type: none"> - UNIVA (elective)*
Postgraduate (6-12 month diploma courses)	<ul style="list-style-type: none"> - UNAM - Universidad de Guadalajara - Universidad Autónoma de Guadalajara 	<ul style="list-style-type: none"> - UNAM - Universidad de Guadalajara - Universidad Autónoma de Guadalajara - Centro de Cuidados Paliativos en Mexico 	<ul style="list-style-type: none"> - UNAM - Universidad de Guadalajara - Universidad Autónoma de Guadalajara 	<ul style="list-style-type: none"> - UNAM - Universidad de Guadalajara - Universidad Autónoma de Guadalajara - Centro de Cuidados Paliativos en Mexico
Specialist (only for physicians)	<ul style="list-style-type: none"> - Universidad Nacional Autónoma de Mexico has a one-year specialization course for doctors specialized in internal medicine, psychiatry, geriatrics, oncology or algology. - The National Institute of Pediatrics offers a super specialization course in pediatric palliative care for pediatricians. - The Institute Jalisciense de Alivio al Dolor y Cuidados Paliativos, the General Hospital of the West and the University of Guadalajara offer a two-year subspecialty program in palliative and pain medicine. - The Autonomous University of Guadalajara plans to start a master’s program in palliative care in March 2015. 			

* The Atlas does not list the names of the nursing schools, faculties of psychology, and faculties of social work that offer palliative care courses in their undergraduate curricula. Human Rights Watch has listed the schools and faculties it was able to confirm.

¹⁰⁷ Ibid.

In July 2014, the Mexican Social Security Institute (IMSS), one of Mexico’s major health insurers, decided to include children’s palliative care into the training program for residents specializing in pediatrics at its affiliate hospitals. Palliative care had previously been included in the curriculum in Guadalajara, where 8 hours of pediatric palliative care have been taught to third year residents in pediatrics since 2011 under “Emerging illnesses and problems.”¹⁰⁸

Medicines Availability

The WHO recommends that countries adopt a “medicines policy in order to ensure the availability of essential medicines for the management of symptoms, including pain and psychological distress, and in particular, opioid analgesics for relief of pain and respiratory distress.”¹⁰⁹ In 2013, the WHO created sections on pain and palliative care in its Model List of Essential Medicines and its Model List of Essential Medicines for Children. These sections contain medicines and specification for formulations that the WHO considers essential for pain management and palliative care.

Under the right to health, countries are required to ensure the availability and accessibility of all medicines included in the WHO Model List of Essential Medicines. The Committee on Economic, Social and Cultural Rights has held that providing essential medicines as determined by the WHO is a core obligation that cannot be limited by claims of limited resources, but states should fulfill immediately.¹¹⁰

As discussed above, there are still significant challenges in Mexico with the availability and accessibility of opioid analgesics. As a study by the Pain and Policy Studies Group at the University of Wisconsin found in 2013, Mexican law contains various provisions that strongly support the need to make opioid analgesics available for medical purposes.¹¹¹ However, implementing regulations create numerous complications in practice, which are

¹⁰⁸ Human Rights Watch communication with Dr. Yuriko Nakashima, July 11, 2014.

¹⁰⁹WHO, “Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course,” http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf.

¹¹⁰ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The right to the highest attainable standard of health, November 8, 2000, para. 43. The Committee on Economic, Social and Cultural Rights is the UN body responsible for monitoring compliance with the International Covenant on Economic, Social and Cultural Rights.

¹¹¹ Pain & Policy Studies Group. *Improving Global Opioid Availability for Pain & Palliative Care: A Guide to a Pilot Evaluation of National Policy*. (Madison: University of Wisconsin Carbone Cancer Center, 2013).

explored in this chapter. While the situation with accessibility of other essential palliative care medicines is better, we also explore challenges in this area.

Access to Opioid Analgesics

You have to help the patient first. If we aren't able to help the patient, the regulations are not good. - Dr. Juan José Lastra, Ajijic, Jalisco¹¹²

Opioid analgesics are essential for the management of pain, shortness of breath and several other common symptoms among people who need palliative care. Because opioid medicines are controlled substances, countries must regulate how they can be produced, distributed, prescribed and dispensed. The 1961 Single Convention on Narcotic Drugs, the international agreement that provides the framework for national drug control efforts, contains four basic requirements for national regulations of controlled medicines:

- Individuals dispensing the medication must be licensed, either by virtue of their professional license or through a special licensing procedure;
- The medications may only be transferred between authorized institutions or persons;
- The medications can only be dispensed to a patient upon a medical prescription;¹¹³ and
- Records on the movement of these medications are kept for no less than two years.¹¹⁴

The Single Convention specifically allows countries to put in place additional requirements, including a special prescription form for controlled medications. Countries, however, have a dual obligation with respects to these medicines: they must ensure their adequate availability for medical and scientific use while preventing their misuse and diversion.¹¹⁵

¹¹² Human Rights Watch interview with Dr. Juan José Lastra, November 11, 2011, Ajijic, Jalisco.

¹¹³ 1961 Single Convention on Narcotic Drugs, Article 30(2bii).

¹¹⁴ *Ibid.*, Article 34.

¹¹⁵ INCB, "Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes," February 2011, http://www.incb.org/documents/Publications/AnnualReports/AR2010/Supplement-AR10_availability_English.pdf (accessed July 11, 2014); INCB, "Availability of Opiates for Medical Needs: Report of the International Narcotics Control Board for 1995," <http://www.incb.org/pdf/e/ar/1995/suppl1en.pdf> (accessed June 28, 2014), p. 1.

Countries must take care that any additional requirements to those specified in the 1961 Single Convention do not unnecessarily impede medical access.¹¹⁶

As noted, international human rights standards require that countries ensure the availability and accessibility of opioid analgesics that are included in the WHO Model List of Essential Medicines. As the manufacturing, prescribing, and dispensing of controlled medicines is subject to strict regulation by governments, states have an obligation to ensure these regulations do not unnecessarily restrict patient access to them for medical purposes. Any regulations that arbitrarily impede the procurement and dispensing of these medications for medical purposes are incompatible with the right to health.

Numerous challenges currently exist with the prescribing of opioid analgesics due to burdensome requirements for physicians and strict and inflexible dispensing rules for these medicines. Mexico's health law and a regulation on medical products and instructions from the country's pharmaceuticals commission set out the rules for prescribing and dispensing medicines.¹¹⁷

The Mexican government, however, has announced significant changes to the prescribing system for opioid analgesics.¹¹⁸ In making the announcement, COFEPRIS stated specifically that these changes aim to improve access to controlled medicines such as morphine for patients with terminal illness.¹¹⁹ Under the new system, which is expected to be operational in the first quarter of 2015, many of the barriers identified here should cease to exist. The specific changes that are being prepared are discussed below, along with descriptions of current barriers.

¹¹⁶ WHO, "Cancer Pain Relief, Second Edition, With a Guide to Opioid Availability," 1996, <http://whqlibdoc.who.int/publications/9241544821.pdf> (accessed June 27, 2014), p. 9.

¹¹⁷ The General Health Law is available at http://www.salud.gob.mx/unidades/cdi/legis/lgs/LEY_GENERAL_DE_SALUD.pdf (accessed on July 15, 2014); the Regulation on Health Products (Reglamento de Insumos para la Salud), available at <http://www.salud.gob.mx/unidades/cdi/nom/compi/ris.html> (accessed July 15, 2014); FEUM y Secretario de Salud, *Suplemento para establecimientos dedicados a la venta y suministro de medicamentos y demás insumos para la salud*, edición 4, México 2010.

¹¹⁸ Announcement of the ministry of health and COFEPRIS of March 28, 2014, available at: <http://t.co/DXLVO444PJ> (accessed June 27, 2014).

¹¹⁹ Announcement of the ministry of health and COFEPRIS of March 28, 2014, available at: <http://t.co/DXLVO444PJ> (accessed June 27, 2014).

Obtaining Prescription Rights

Under current Mexican law, a physician must obtain a special license, triplicate prescription forms, and barcoded stickers in order to be able to prescribe opioid analgesics.¹²⁰ These requirements go well beyond what the 1961 Single Convention mandates. The WHO has noted that requirements for duplicate prescriptions and special prescription forms increases the administrative burden both for healthcare workers and drug control authorities. It has stated that this problem is “compounded if forms are not readily available, or if health professionals need to pay for them.” It recommends that countries should “ensure that this system does not impede the availability and accessibility of controlled medicines.”¹²¹

Obtaining the license to prescribe opioid analgesics. In order to obtain the license to be allowed to prescribe opioids, the medical doctor must apply to the health department or COFEPRIS office in their state.¹²² This can only be done in the state capital and must be done in person, a disincentive for doctors who work outside of capital cities. The license is generally not issued the same day, meaning doctors may have to return a second time to finalize proceedings. Although an explanatory note of the health ministry and COFEPRIS clearly states the process is free of charge, some Mexican states charge an application fee for obtaining the license, creating an additional financial burden (see Table 3 below).¹²³ Under the changes that are being prepared, physicians will be able to request and obtain these licenses through an online procedure and will no longer have to make physical appearances as part of this process.¹²⁴

The special prescription form. Physicians must order special triplicate prescription forms in order to prescribe opioid analgesics, again requiring additional expenditure on their part. Problematically, the rules for these forms require that they contain the physician’s

¹²⁰ See Ley General de Salud, article 241, for the requirement that prescriptions contain a barcoded sticker. More detailed requirements can be found in the Suplemento of 2010, p. 147.

¹²¹ WHO, “Ensuring Balance in National Policies on Controlled Substance: Guidance for Availability and Accessibility of Controlled Medicines,” 2011, http://whqlibdoc.who.int/publications/2011/9789241564175_eng.pdf?ua=1 (accessed July 11, 2014), p.28.

¹²² See article 51 of the regulation on health products (Reglamento de Insumos para la Salud) and the suplemento. The Ministry of Health and COFEPRIS also issued an explanatory note (circular in Spanish) in October 2005 which contains additional details on the process. The explanatory note can be found at <http://www.ipomex.org.mx/ipo/archivos/downloadAttach/167845.web;jsessionid=0DD959939C1E283B82E8B99C63993632> (accessed July 11, 2014).

¹²³ See Explanatory note of October 2005.

¹²⁴ Human Rights Watch meeting with Mikel Arriola-Peñalosa, commissioner of COFEPRIS, September 3, 2014.

home address.¹²⁵ This requirement does not appear to serve any useful purpose from a drug control or medical perspective but does pose a potential security risk for the prescribing physician. Several doctors told us that this requirement is a deterrent. As one doctor commented, “I only give my home address to people I trust, not to everybody. So I don’t know why your house phone and your address have to be in the prescription.”¹²⁶ The government has announced that this requirement will be eliminated.¹²⁷

Bar coded stickers. The most significant disincentive to prescribing opioid analgesics is the very unusual requirement in Mexico’s general health law that prescriptions for these medications must carry a barcoded sticker.¹²⁸ A variety of factors makes the current system for barcoded stickers very user-unfriendly and discourages physicians from prescribing these medications:

- The stickers can only be issued by the health and sanitation authorities at one location in each state’s capitals, usually the health ministry or COFEPRIS office, which are open only during business hours.¹²⁹
- Doctors must collect the stickers in person.¹³⁰
- Regulations allow health departments to issue only fifty pairs of stickers at once.¹³¹
- In most states, the stickers are not prepared immediately so the physician must return to collect them later, sometimes several weeks later.

¹²⁵ See Suplemento, p. 147. The requirement does not appear to be uniformly enforced. Several doctors told us that their work address or the address of their private clinic is on the prescription form rather than their home address.

¹²⁶ Human Rights Watch interview with Dr. Juan José Lastra, November 11, 2011, Chapala, Jalisco.

¹²⁷ Human Rights Watch meeting with Mikel Arriola-Peñalosa, commissioner of COFEPRIS, September 3, 2014.

¹²⁸ Article 241, Ley General de Salud. One sticker must be placed on the copy of prescription for the pharmacy, another on the copy for the patient. The physician’s copy does not require the sticker. In some hospitals, such as the National Cancer Institute, doctors are allowed to write internal hospital prescription forms for medications of Group I that patients can fill at the pharmacy of that hospital. In such cases, no barcoded stickers are needed. However, this appears to be practiced only in some hospitals.

¹²⁹ See explanatory note of October 2005.

¹³⁰ Some physicians told us they are allowed to send someone else to request the barcoded stickers for them.

¹³¹ Official instructions regarding the prescription of controlled medicines belonging to group I specify that the first time a doctor requests barcoded stickers, the health authority issues a set of fifty (Suplemento, p. 147). The instructions do not specify a limit for subsequent requests but October 2005 explanatory note specifies that barcoded stickers are always provided in sets fifty. This rule, however, has not been followed strictly as some physicians have been able to get a hundred pairs of stickers at a time. At a round table on palliative care in June 2014 in México City in which Human Rights Watch participated, representatives of COFEPRIS said that the agency is now routinely issuing a hundred pairs of stickers to facilitate the prescribing of controlled medicines.

- Some states charge physicians for barcoded stickers (see Table 3).
- Some of the machines used to print the stickers are outdated and are reported to break down frequently, resulting in states being unable to issue new stickers for weeks or even months at a time.¹³²

This system is difficult for all physicians but especially for those who live outside of state capitals. They must travel to the state capital—a trip that can often take hours—at least once for every batch of barcoded stickers they need. If the health department or COFEPRIS do not issue the stickers immediately, they may have to travel a second time. If the machine that prints the stickers is broken, a trip to the capital can be altogether futile.

A general practitioner in Ajijic, about an hour away from Guadalajara, told Human Rights Watch that he needs a new set of fifty barcoded stickers every two weeks and thus has to make the trip to the city every fortnight. He said that he loses half a day of work each time.¹³³ Another doctor from the same town said he has to close his private clinic early on days he needs to travel to Guadalajara to pick up barcoded stickers:

My consultations are in the mornings and they [the health department] are open only in the mornings. So some days I'll have to go at 1pm as they close at 3pm. For me it means losing patients or seeing fewer patients.¹³⁴

¹³² COFEPRIS has been replacing these machines with a new system that allows barcoded stickers to be printed from any printer.

¹³³ Human Rights Watch interview with Dr. Juan José Lastra, November 11, 2011, Chapala, Jalisco.

¹³⁴ Human Rights Watch interview with Dr. Carlos García, November 11, 2011, Chapala, Jalisco.

Table 3 – Fees for Licenses to Prescribe Opioids and Barcoded stickers¹³⁵

State	Charge for License	Charge per set of 50 stickers	Processing of Stickers
Baja California Sur	606 pesos (US\$46.69)	472 pesos (US\$36.36)	5 days
Chiapas	650 pesos (US\$50.8)	No charge	10 days
Colima	No charge	887 pesos (US\$68.34)	5 days
Mexico State	318.85 pesos (US\$25.56) or 336 pesos (US\$25.89)*	318.85 pesos (US\$25.56) or 336 pesos (US\$25.89)*	2 days
Guerrero	1228 pesos (US\$86.90) or 1295 pesos (US\$99.77)*	614 pesos (US\$47.30) or 648 pesos (US\$49.92)*	10 days
Querétaro	No charge	200 pesos (US\$15.41)	Not available
San Luis Potosí	638 pesos (US\$49.15)	638 pesos (US\$49.15)	Not available
Sinaloa	No charge	150 pesos (US\$11.56)	Not available
Tamaulipas	63.77 or 67.29 pesos (US\$4.91 or 5.18)]*	63.77 or 67.29 pesos (US\$4.91 or 5.18)]*	26 days
Yucatán	No charge	689 pesos (US\$53.08)	3-4 days

* The higher fees generally apply in major urban areas.

Even for physicians who live in state capitals, collecting the barcoded stickers can be a time-consuming affair. In Mexico City, a city of almost nine million people and notoriously heavy traffic, there is just one office, the headquarters of COFEPRIS, that can issue the stickers. Opening hours are 8am to 2pm, coinciding exactly with hours of medical consults in most hospitals. Dr. Argelia Lara, the head of the pain clinic at Instituto Nacional de

¹³⁵ This table is based on information received through requests under México's freedom of information act in 2012 (Campeche, Chiapas, Colima, Durango, Querétaro, Quintana Roo, San Luis Potosí, and Sinaloa), web searches (Campeche, Chiapas, Colima, Durango, Guerrero, Querétaro, Quintana Roo, and Tamaulipas), and phone calls (Baja California Sur, México State, San Luis Potosí, Tamaulipas and Yucatan). In the cases of Campeche, Durango, and Quintana Roo, official responses to our freedom of information requests indicated that the states charge for licenses or barcoded stickers (Campeche: 75 pesos (US\$5.78) per set of barcoded stickers; Durango: 797.58 pesos (US\$61.45) for license and per set of barcoded stickers; Quintana Roo: 63.77 to 637.70 pesos (US\$4.91 to US\$49.10) for the license) whereas government webpages, which were consulted in 2014, said the process was free. In some cases, the fee stated online differed from the one stated in responses to freedom of information requests (Chiapas reported that the cost of the license was 1118 pesos (US\$86.13) in its response to the freedom of information request; San Luis Potosí responded that the charge for the license and per set of barcoded stickers was 591 pesos (US\$45.53). We included the more recent information. In some states, the first set of barcoded stickers (México State and San Luis Potosí) is issued free of charge. All responses to freedom of information requests are on file with Human Rights Watch.

Ciencias Médicas y Nutrición Salvador Zubirán (hereinafter Hospital Nutrición), a tertiary level hospital in Mexico City, told us:

By car it takes an hour to get to the office—if it isn't rush hour, that is...another [hour] out there [at COFEPRIS] and another to return. In total three hours so you have to dedicate your whole morning to the process.¹³⁶

Moreover, COFEPRIS in Mexico City does not issue the barcoded stickers the same day. According to Dr. Lara, it usually takes two weeks before she can pick up the stickers. She notes that the waiting time varies greatly, making it difficult for her to plan. Dr. Lara uses a set of barcoded stickers every five weeks on average but the number of patients and their symptoms vary so it is important that she always has an ample supply of barcoded stickers. Otherwise, she may run out of them before having received a new set preventing her from prescribing opioid analgesics to patients who require them.

As Table 3 shows, some states informed Human Rights Watch that they charge a fee for either the license to prescribe opioids, packages of barcoded stickers or both, despite the fact that COFEPRIS maintains the process of obtaining barcoded stickers is free of charge.¹³⁷ It is unclear whether these charges are always enforced as some physicians told us that they were able to get the license or barcoded stickers free of charge even though the state government claims it charges a fee.

Numerous physicians interviewed during our research complained that the machines used to print barcoded stickers were antiquated and regularly broke down. As there was only one machine per state, this resulted in serious problems for physicians and their patients when the machine was out of order. In Mexico City, for example, the machine broke down in 2012 and was out of order for a period of five months. Dr. Lara of Hospital Nutrición told Human Rights Watch:

We did not have prescriptions for almost five months and they did nothing. [For a long time] there was no resolution and nobody was providing anyone any information on what was happening.

¹³⁶ Human Rights Watch interview with Dr. Argelia Lara, México City.

¹³⁷ Response to freedom of information request 121510000212 of February 1, 2012. On file with Human Rights Watch.

She said that the situation has improved somewhat since that time: “Before it was horrible. The environment was chaotic. The system went down all the time. Now it is a bit better and the place is larger and has more personnel.”¹³⁸

The machine also broke down for an extended period of time in Veracruz in 2013. Dr. Rafael Contreras of the Centro Estatal de Cancerología del Estado de Veracruz told Human Rights Watch in March 2013 that because of the malfunction, barcoded stickers for Veracruz were being printed in Puebla, a neighboring state. As a result, it took more than a month from the time new stickers were requested until they could be picked up.¹³⁹

Under the announced reforms to the prescribing system for this class of medicines, the government plans to institute an electronic process for barcoded stickers. Physicians will be able to request 100 sets of barcoded stickers at a time, download these onto their computers and print them.¹⁴⁰ Provided the electronic system works smoothly, it should eliminate most of the difficulties physicians currently encounter in obtaining barcoded stickers.

Licensing of Pharmacies

Under Mexican regulations, pharmacies must obtain a special license to be able to buy and sell opioid medications and they must keep detailed books of any sales.¹⁴¹ We interviewed about a dozen managers of pharmacies, who had obtained this license or were in the process of doing so, and they described the process as relatively unproblematic. They said obtaining the license did require a certain amount of paperwork and that it can take several months to receive final approval but that was not overly complex. They also said that record keeping requirements are more stringent than for regular medications, although they did not consider that to be a significant problem.¹⁴²

In contrast, about a dozen managers and other staff of pharmacies who did not have the license often cited the perceived hassle of carrying opioid analgesics. They said that it would be difficult to get the license, that the paperwork involved in accounting for the comings and

¹³⁸ Email correspondence with Dr. Argelia Lara, April 7, 2014.

¹³⁹ Email correspondence with Dr. Rafael Contreras Bello, March 6 and 25, 2013.

¹⁴⁰ Human Rights Watch meeting with Mikel Arriola-Peñalosa, commissioner of COFEPRIS, September 3, 2014.

¹⁴¹ See Suplemento, chapters VII and XV.

¹⁴² Human Rights Watch interviews with managers of pharmacies in Guadalajara, Jalisco, and Tuxtla-Gutiérrez, Chiapas.

goings of these medicines would be cumbersome, and that they would be subject to additional and invasive inspections by officials of their management of opioid analgesics.

But the main reason these pharmacy staff identified for not getting the license was the lack of demand for these medicines. The manager of a pharmacy in Tepatitlán, Jalisco, for example, told us: “It doesn’t make economic sense. We can’t return these medicines so they will expire. People don’t request the medicines.”¹⁴³ Given how few physicians prescribe these medicines, especially outside of the major cities, this is hardly surprising.

Several pharmacists identified the fact that they must provide the state health department with a projection for the amount of opioid analgesics they expect to need for a six month period as a problem. They said that if it turns out during that period that they need more of a certain medication they have to wait for the next six month period to adjust their estimate.¹⁴⁴ As a result, pharmacies may run out of the medication, which can be difficult for patients as so few pharmacies carry opioid analgesics.

Problems with Dispensing of Opioid Analgesics

How often do patients have to return to get a new prescription? All the time!
– Pharmacy manager in Guadalajara¹⁴⁵

Easily 15% of my barcoded stickers are lost...Why is it so difficult? It's hard for the doctor, hard for the patient and hard for the pharmacy. It should be much simpler – Dr. Jesús Medina¹⁴⁶

In interviews with patients, family members, physicians and pharmacists we heard dozens of reports of pharmacies refusing to fill prescriptions for opioid analgesics because of errors or non-compliance with official rules. Some physicians estimated that pharmacies cannot fill as many of 15 to 30 percent of the prescriptions they write for opioid analgesics.

¹⁴³ Human Rights Watch interview with manager of Buenavides pharmacy in Tepatitlán, February 24, 2012.

¹⁴⁴ Suplemento, chapter XV.

¹⁴⁵ Human Rights Watch interview with the manager of a pharmacy in Guadalajara, February 21, 2012.

¹⁴⁶ Human Rights Watch interview with Dr. Jesús Medina, Guadalajara, November 16, 2011.

These refusals are major inconveniences for people with life-limiting illnesses and their relatives. When a pharmacy cannot fill their prescription they have to return to their physicians for a new prescription. Such a trip—followed by a second trip to the pharmacy—can take many hours and may temporarily leave the patient without their medicines. For doctors, rejected prescriptions are a problem because they lead to a waste of barcoded stickers that, as described above, are hard to get.

We found that the rejection of these prescriptions is generally due to a combination of factors, including limited and unreliable stock of these medicines at pharmacies, excessive caution in handling this class of medicines at some pharmacies, inspections by departments of health that sometimes appear to encourage this, and finally, a lack of flexibility in the prescribing and dispensing rules that would allow for the problem to be resolved without an extra trip to the physician.

Most of the rejections of prescriptions we learned about were related to one of the following requirements:

- The requirement that the prescription covers a period of no more than thirty days;¹⁴⁷
- Challenges with correcting minor, technical errors on prescription forms for opioid analgesics by pharmacies;¹⁴⁸
- The requirement that prescriptions for opioid analgesics contain both the commercial and generic name of the medicine;¹⁴⁹
- The lack of authority for pharmacies to substitute the medicine or formulation indicated in the prescription form, even after consultation with the prescribing physician, if they are out of stock of the requested medicine.¹⁵⁰

¹⁴⁷ See Sección B. Requisitos Para El Surtido de Recetas, Capítulo XV: Medicamentos Controlados, Suplemento.

¹⁴⁸ Chapter XV of the Suplemento allows the person in charge of the pharmacy (in Spanish: responsable sanitario) to make corrections to prescriptions after requesting clarification from the prescribing physician. However, it is common that the person in charge is not at the pharmacy and the regulations do not allow regular pharmacy staff to make corrections.

¹⁴⁹ See: Sección E. Formato del Recetario Especial, Capítulo XIV: Receta Médica, Suplemento; and Article 31 of the Reglamento de Insumos para la Salud, available at <http://www.salud.gob.mx/unidades/cdi/nom/compi/ris.html> (accessed July 11, 2014).

¹⁵⁰ Ibid.

In a meeting with Human Rights Watch in September 2014, Mikel Arriola, the head of COFEPRIS, agreed to make two key changes to the prescribing rules, which could help avoid many of the cases of canceled prescriptions we documented.¹⁵¹ He also agreed that COFEPRIS would hold periodic meetings with the pharmaceutical industry, pharmacies and prescribers to try to identify potential challenges with the supply of morphine so as to avoid stock-outs.

Compliance with the 30-day Prescription Limit

...at times you have to invent things: the dose, the number of tablets so that they don't return them [the prescriptions]. – General practitioner¹⁵²

Mexican prescription rules for opioid analgesics limit the number of days a prescription for such medicines may cover to thirty days.¹⁵³ This limitation is not unreasonable. Indeed, most countries in the region impose a similar limit, although a few countries—Belize, Paraguay, St Lucia and Uruguay—leave it to the discretion of the prescriber.¹⁵⁴

Yet, this limit creates a number of significant problems in Mexico because pharmacies only dispense ready-made packages of medications. In other words, pharmacies do not count out the exact number of tablets or ampoules indicated on the prescription form but sell pre-packaged units.¹⁵⁵ Current practice is that if the amount of medication in a package exceeds the amount prescribed for the thirty days period, the pharmacy cannot dispense.

The amount of medications a patient needs over a 30 day period often does not coincide with the contents of available prepackaged boxes.¹⁵⁶ For example, Dr. Carlos García, a general practitioner in Ajijic, Jalisco, told us: “If the box comes with 100 tablets but the

¹⁵¹ Human Rights Watch meeting with Mikel Arriola-Peñalosa, September 3, 2014, México City.

¹⁵² Human Rights Watch interview with a general practitioner who requested to remain anonymous.

¹⁵³ See Sección B. Requisitos Para El Surtido de Recetas, Capítulo XV: Medicamentos Controlados, Suplemento.

¹⁵⁴ Jim Cleary et al., “Formulary Availability and Regulatory Barriers to Accessibility of Opioids for Cancer Pain in Latin America and the Caribbean: A Report from the Global Opioid Policy Initiative (GOPI),” *Annals of Oncology* 24 (2013): xi41–xi50, accessed July 11, 2014, 2013, doi:10.1093/annonc/mdt502.

¹⁵⁵ Most pharmacies in México do not employ anyone with training in pharmacy.

¹⁵⁶ It is accepted practice for physicians to include rescue doses in prescriptions for opioid analgesics, which can be used when a patient experience pain that is not controlled by the prescribed dose. When the amount of excess medication is small, physicians generally designate the leftovers as rescue doses.

patient only needs 60 they won't sell you the prescription."¹⁵⁷ Physicians told Human Rights Watch that this forces them to revert to trickery to be able to prescribe the medications. One pain specialist, who requested anonymity because of potential legal implications, said: "I can't leave my patients without medications. So I fill out the prescription as if it would end in 30 days even though I know it will last him [longer]..."¹⁵⁸

Many doctors said they give patients two prescriptions: One (on the official prescription form with bar coded sticker) that has fictional daily doses of the medication adjusted to fulfill regulatory requirements and used only to get the medications from the pharmacy; the other (on a separate regular prescription form) with actual instructions to the patient on the doses and frequency with which the medications should be taken. One doctor gave the following example:

Sometimes patients require just a little more than 100 [tablets]...say 120 tablets per month. To give them 120 tablets I have to prescribe two boxes of 100 tablets and invent that they have to take more [six per day instead of four]. Otherwise, they won't give [the medication] to them. Imagine, if I need 120 tablets that means I'll have 80 left over. So we're complying with the rule. The rule isn't violated. But sometimes the rule is so inflexible that it obliges one to do things like this.¹⁵⁹

A system that forces physicians to write prescriptions that do not correspond to the actual dosage prescribed for the patient is obviously problematic, especially as it can lead to confusion among patients and their families regarding the instructed dosage.

¹⁵⁷ Human Rights Watch interview with Carlos García, November 11, 2011, Chapala, Jalisco.

¹⁵⁸ Human Rights Watch interview (name is withheld at the request of the physician).

¹⁵⁹ Human Rights Watch interview (name is withheld at the request of the physician).

Table 4. Oral opioid formulations¹⁶⁰

Medication	Brand name	Formulation	Tablets per package
Hydromorphone	Liberaxim	2mg	100 tablets
Methadone	Rubidexol	5mg	100 tablets
		10mg	100 tablets
	Amidone	40mg	100 tablets
Morphine	Analfin	10mg	20 or 100 tablets
		15mg	20 or 100 tablets
		30mg	20 or 100 tablets
	Graten	30mg	20 or 100 tablets
Oxycodone (immediate release)	Endocodil	5mg	15, 30, or 100 tablets
		10mg	15, 30, or 100 tablets
		20mg	15, 30, or 100 tablets
		40mg	15, 30, or 100 tablets
Oxycodone (w paracetamol)	Plexicodim	5mg/325mg	100 tablets
Oxycodone (extended release)	Oxycontin	10mg	30 tablets
		20mg	30 tablets
		40mg	30 tablets

Commercial and generic names. The rules for special prescription forms do not directly require that the physician indicate both the generic and commercial name of the opioid analgesic.¹⁶¹ However, the rules for health supplies determine that for medicines not included in Mexico’s catalogue of generic medicines—and none of the opioid analgesics are—it is obligatory that the commercial name of the medicine be indicated on the prescription form.¹⁶² The rules establish furthermore that when the prescription contains the commercial name of the medicine the pharmacy can only dispense that denomination and “may only substitute it when expressly authorized by the prescriber.”¹⁶³

¹⁶⁰ Information obtained from COFEPRIS’ medicines database at <http://189.254.115.245/BuscadorPublicoRegistrosSanitarios/BusquedaRegistroSanitario.aspx> (accessed July 16, 2014).

¹⁶¹ Sección E. Formato del Recetario Especial, Capítulo XIV: Receta Médica, Suplemento.

¹⁶² Article 31 of the Reglamento de Insumos para la Salud, available at <http://www.salud.gob.mx/unidades/cdi/nom/compi/ris.html> (accessed July 11, 2014).

¹⁶³ Article 31 of the Reglamento de Insumos para la Salud states: “The person who issues the prescription shall prescribe the medicines in accordance with the following:

As a result of these rules, pharmacies refuse to dispense opioid analgesics if the commercial name of the medicine is not indicated in the prescription. Similarly, they are not allowed to dispense alternatives of the same medicine with a different commercial name, even if they consult with the prescribing physician. For example, if a patient has a prescription for morphine tablets under the commercial name Graten (produced by PISA Pharmaceuticals) but the pharmacy has only Analfin (morphine tablets produced by Tecnofarma) it cannot dispense the morphine when the dosage and formulation are the same.

Miguel Márquez, the brother of Alejandra, said that morphine had recently run out in various pharmacies in Guadalajara.

Right now there isn't any in Farmacias Guadalajara or in Benavides [another pharmacy], only in Farmacias Especializadas. They have to sell them. It's necessary. This is for a pain that is sharp. It's as I said sometimes the pain hits her it can be for four hours and she cries and screams.¹⁶⁴

While these rules were clearly not intended to complicate access to opioid analgesics, both doctors and patients told us this is a significant issue for them. The problem is particularly acute because pharmacies maintain limited stock of opioid analgesics due to the limited use of these medicines in Mexico and the fact that supply is not always reliable. As a result, pharmacies frequently run out of stock of certain medicines and/or formulations.

In the above-mentioned meeting with Human Rights Watch, COFEPRIS agreed to a change in prescription rules to allow physicians to indicate only the active substance (or generic name) on prescription forms as opposed to the commercial name.¹⁶⁵

I. In case the medicines are included in the Catalogue of Interchangeable Generic medicines, referred to in article 75 of this order, he shall note the generic denomination and, if so desired, he can indicate the specific denomination of his preference; and

II. In case of medicines that are not included in the catalogue referred to in the previous provision, he shall equally include the specific denomination or jointly the generic and specific denomination.

When the prescription indicated the specific denomination of the medicine the sale or application must be agree exactly with this denomination and can only be substituted when expressly authorized by the prescriber.”

¹⁶⁴ Human Rights Watch interview with Esmeralda and Miguel Márquez (pseudonyms), November 12, 2011, Guadalajara.

¹⁶⁵ Human Rights Watch meeting with Mikel Arriola-Peñalosa, September 3, 2014, México City.

Lack of flexibility to make technical corrections to prescriptions for opioid analgesics.

Under current regulations, only the person in charge of pharmacies, the *responsable sanitario*, can correct technical or clerical errors on the prescription after consulting the prescribing physician. When this official is not present, which is very common, Mexico's rules do not permit corrections so the patient must return to the physician for a new prescription. Errors may include an illegible diagnosis, a mistake in the spelling of the name of the patient, or an error in the formulation of the medication (for example, 50mg tablets of methadone, which do not exist in Mexico, instead of 5mg). A doctor at a pain clinic in Guadalajara, for example, said:

There are pharmacies that are very over sensitive. If I put Sector Libertario [a neighborhood in Guadalajara] as "SL" or if I put down "GDL" or "GAL" [for Guadalajara], they refuse to fill it.¹⁶⁶

The WHO recommends that "in order to start the prescribed therapy in a timely manner, legislation should address the pharmacist's ability to correct technical errors in prescriptions."¹⁶⁷

Substituting formulation of medication. Under current rules, there is no mechanism to adjust the formulation of opioid analgesics when the formulation indicated on the prescription form is not available. Thus at present, a pharmacy would not be able to dispense 10mg morphine tablets to a patient with a prescription for 30mg morphine tablets even if the latter are unavailable. Patients told us that as stock is often limited and few pharmacies carry opioid analgesics, which is frequently a problem. At present, even a faxed or emailed correction from the prescribing physician is not sufficient to allow the pharmacy to substitute the formulation. Dr Jesús Medina of Instituto Paliat told Human Rights Watch: "Patients often return. They say: 'Doctor, this medication is out. They don't have it in the pharmacy. They only have this strength. What do I do?' 'Doctor, can you write a new prescription?'"¹⁶⁸

¹⁶⁶ Human Rights Watch interview with Dr. Gerardo Rodríguez, November 16, 2011, Guadalajara.

¹⁶⁷ WHO, "Ensuring Balance in National Policies on Controlled Substance: Guidance for Availability and Accessibility of Controlled Medicines," http://whqlibdoc.who.int/publications/2011/9789241564175_eng.pdf?ua=1, p. 30.

¹⁶⁸ Human Rights Watch interview with Jesús Medina, November 16, 2011, Guadalajara.

During the above-mentioned meeting, the head of COFEPRIS suggested that prescription rules could be changed to allow physicians to indicate multiple alternatives for dosages on prescription forms.¹⁶⁹ In other words, physicians would be able to indicate that the pharmacist could dispense tablets of 30mg or twice the number of tablets of 15mg. Such change to the rules would greatly facilitate the dispensing of these medicines.

Some pharmacists told us that inspections by the health department had made them more cautious about dispensing opioid analgesics. For example, the manager at Farmacia Maypo in Guadalajara said the health department had criticized him for dispensing a prescription for one hundred tablets of morphine that did not specify whether it should consist of one box of one hundred tablets or five boxes of twenty. The manager said:

We did not have that kind of control before. Before, you could say: “Here you go” when you got that kind of prescription. Since they came, we [reject] prescriptions more frequently.¹⁷⁰

The manager of another pharmacy told us: “There are complaints because of the formulations. They fine us. With controlled medicines, there is no flexibility. They are very strict.”¹⁷¹

¹⁶⁹ Human Rights Watch meeting with Mikel Arriola-Peñalosa, September 3, 2014, México City.

¹⁷⁰ Human Rights Watch interview with the manager of Maypo Farmacias, February 20, 2012, Guadalajara.

¹⁷¹ Human Rights Watch interview with the manager of a pharmacy, February 21, 2012, Guadalajara.

Stock-Outs of Morphine

Medical doctors from each of the regions where we conducted research said they frequently faced stock-outs of opioid medicines. A palliative care doctor from Chiapas said, for example: “Stock-outs of morphine are a key factor that limits our use [of the medicine].”¹⁷² To obtain a snapshot of current stock-outs, we surveyed palliative care physicians and pharmacists at institutions in Chiapas, Jalisco, Nuevo León and Mexico City who told us the following about stock-outs they had experienced in 2014.

Jalisco: “At this moment we have a stock-out of morphine in tablets in the metropolitan area [of Guadalajara]. We don’t have tablets of 15 and 30mg of either brand. There are just a few boxes of Analfin [one of the brands] with 20 tablets of 10mg left. This has been going on for two weeks and according to the representative [of Tecnoforma, which produces Analfin] we won’t have [a new supply of morphine] until mid-September.”¹⁷³

Mexico City: “In April and May, we were altogether without morphine. Now there are tablets of 10mg but not of 15 or 30mg. I currently have a patient with advanced cancer for whom taking three times as many tablets is difficult because she has trouble swallowing. My only alternative is to prescribe Oxycodone, which is available, but six times more expensive.”¹⁷⁴

Nuevo León: “We have not had difficulties with oral morphine in Monterrey but recently we’ve had a stock-out of injectable morphine. I currently have a patient with cancer who needs high doses of morphine and I have to switch her to different opioids because the pharmacy has been informed that they won’t get any more [stock in the immediate future].”¹⁷⁵

¹⁷² Email correspondence with Dr. José Antonio Córdova Domínguez, July 23, 2014.

¹⁷³ Email correspondence with Alan Ruiz, pharmacist at Instituto Palia, July 21, 2014.

¹⁷⁴ Telephone interview with Dr. Argelia Lara of Hospital Nutrición, July 25, 2014.

¹⁷⁵ Email correspondence with Dr. Víctor Silva of Centro Médico Zambrano Hellion, July 23, 2014.

Chiapas: “Pharmacies do not have stock of the different formulations or continuity of stock over time. This means we cannot maintain effective pain therapy over time.”¹⁷⁶

We did not specifically investigate the reasons for these stock-outs although interviews suggest they are likely caused by a combination of factors, including lack of demand for these medicines, the limited number of pharmaceutical companies producing them, regulatory complexities around the importation of raw materials, inadequate communication, and problems with compliance with regulations on handling opioid materials. On September 12, 2014, COFEPRIS and Mexico’s member of the International Narcotics Control Board, Dr. Alejandro Mohar-Betancourt, hosted a first meeting of pharmaceutical companies, pharmacies and healthcare providers to identify and overcome challenges with the supply of morphine.¹⁷⁷

Barriers to Access to Opioid Analgesics in Home Care

While Mexican law encourages home-based palliative care current regulations do not authorize physicians who conduct home visits to patients to carry opioid analgesics.¹⁷⁸ Under current regulations home teams should leave families with prescriptions so that a family member can go to the pharmacy to buy the medications. This seems to defeat the purpose of home-based palliative care.

Some home teams have developed a trick that allows them to bring medications with them and leave them with the patients. As regulations allow people to carry opioid medications if they have a filled out prescription form with barcoded sticker, these home-care physicians write a fictitious prescription for opioid analgesics, with barcoded stickers, before they head out to visit patients in their homes. This prescription allows them to carry the medicines. At patients’ homes, they conduct an examination in order to determine the

¹⁷⁶ Email correspondence with Dr. José Antonio Córdova Domínguez, July 23, 2014.

¹⁷⁷ A Human Rights Watch researcher participated in the meeting.

¹⁷⁸ Section III of the Reglamento de Insumos para la Salud (the Regulation on Medical Supplies) regulates how narcotic drugs and psychotropic substances may be handled. It does not make any provision for home-based palliative care teams to carry opioid medicines. Available at <http://www.salud.gob.mx/unidades/cdi/nom/compi/ris.html> (accessed on July 24, 2014).

dosage the patient actually needs at which point they may need to write another prescription for the actual amount of medication the patient requires.

The existence of these restrictions is not surprising. Drug regulations in most countries were written before the home-based and primary-care models for palliative care began to develop. Regulations, however, need to be modernized to reflect current needs and practices. Just as Mexican regulations authorize—indeed oblige—certain ambulances to carry injectable morphine, they should specifically allow home-based palliative care teams to bring supplies of opioid medicines to their patients without having to waste prescription forms.¹⁷⁹

Inclusion of Essential Palliative Care Medicines in Mexico's Medicines' Lists

Since 2013, the WHO Model List of Essential Medicines contains a section on pain and palliative care that includes a total of twenty medications in three categories: non-opioids and non-steroidal anti-inflammatory medicines, opioid analgesics, and medicines for other common symptoms in palliative care patients. The WHO recommends that these medicines be available to all who need them in the formulations indicated in the list. The May 2014 World Health Assembly resolution recommends that all countries adjust their national medicines lists accordingly.

In Mexico, the Council of Public Health (Consejo de Salubridad General) is responsible for preparing and updating the list of essential medicines (in Spanish: Cuadro Básico y Catálogo de Medicamentos). This list forms the basis of the medicines lists of Mexico's health insurers, such as Seguro Popular and IMSS.¹⁸⁰ The list was last updated in 2013.

A comparison of the WHO's list and the medicines lists of the Council, Seguro Popular and IMSS reveal a number of important differences (see Appendix 2), including:¹⁸¹

¹⁷⁹ Norma Oficial Mexicana, NOM-237-SSA1-2004, Regulación de los servicios de salud. Atención prehospitalaria de las urgencias médicas. (Regulation of Health Services. Pre-hospital attention for medical emergencies, see Appendix normativo C. Available at <http://www.salud.gob.mx/unidades/cdi/> (accessed on July 25, 2014).

¹⁸⁰ "Cuadro Básico y Catálogo de Medicamentos del Consejo de Salubridad General," undated, <http://www.cofepris.gob.mx/MJ/Documents/AcuerdosConsejoSalubridadGeneral/250214csgmedicamentos.pdf> (accessed on September 16, 2013).

¹⁸¹ The Universal Catalogue of Health Services (Catálogo Universal de Servicios de Salud) of March 2014 is on file with Human Rights Watch. "Cuadro Básico de Medicamentos del Instituto Mexicano del Seguro Social," undated, <http://www.imss.gob.mx/sites/all/statics/pdf/cuadros-basicos/CBM.pdf> (accessed on September 16, 2013).

- None of the Mexican lists contain a pain and palliative care section. Instead, as in earlier versions of the WHO's list, palliative care medications are spread out over six different sections, including analgesia, anesthesia, psychiatry, rheumatology, gastroenterology and oncology. As a result, medicines that may be needed for the provision of palliative care to a patient with heart disease may be categorized as medicines for cancer or psychiatry. This may lead to reluctance among physicians to prescribe these medicines.
- Five medicines that the WHO considers essential for palliative care are not included in any of Mexico's lists: docusate sodium, cyclizine, hyoscine hydrobromide (on the WHO Model List of Essential Medicines for Children), ibuprofen, and lactulose. According to a Mexican pharmacist specialized in palliative care, Mexico's lists do not contain an adequate substitute for the first three of these medicines.¹⁸²
- Key formulations, mostly oral solutions and suppositories, for eight medicines on the WHO list are missing from Mexico's lists.¹⁸³ This complicates administration to patients who have trouble swallowing or have uncontrollable nausea, neither of which is uncommon in palliative care patients. Oral solutions are also essential for many young children.
- Finally, Mexico's essential medicines lists specify at what levels of care medicines should be available whereas the WHO recommends that all essential medicines be available at all levels of care.¹⁸⁴ The Council's list, for example, designates six of the essential palliative care medicines—opioid analgesics, several medicines

¹⁸² Email communication with Raymundo Escutia, head of the department for inter-hospital networking at the Jalisco mental health institute, secretary of the Iberian and Latin American Organization of Pharmacists and former head of pharmacy at Instituto Palia. Metamizol is an adequate substitute for ibuprofen and plantago psyllium can be used as a substitute for lactulose.

¹⁸³ These are: suppositories of ácido acetilsalicílico, oral solution of metamizol (ibuprofeno), oral solution of morphine, Gránulos de morfina, oral solution of dexametasona, rectal solution of Diazepam, oral solution of midozalam, and oral solution of ondansetron.

¹⁸⁴ See explanatory note to the WHO Model List of Essential Medicines of April 2013, October 2013, http://apps.who.int/iris/bitstream/10665/93142/1/EML_18_eng.pdf?ua=1 (accessed July 11, 2014).

routinely used in patients with anxiety, and an anti-nausea medicine—for use only in secondary and tertiary care facilities.

These discrepancies are likely to lead to inadequate treatment for patients who require palliative care.

IV. Mexico's Legal Protections for Patients in Need of Palliative Care

In 2009, Mexico enacted a series of amendments to its health law to better address the healthcare needs of people with terminal illnesses. The amendments pursued several objectives, including:

- To ensure the dignity of people in the terminal stages of disease through the necessary medical care to maintain their quality of life;
- To ensure a natural death in dignified circumstances;
- To establish and guarantee the rights of the person in terminal state with respect to his treatment;
- Determining the limits between the protection of life and futile care (in Spanish: *obstinacion terapeutica*).¹⁸⁵

They set out a series of rights of people with terminal illness and their families, as well as powers and obligations of health institutions and healthcare personnel. In 2013, the government issued additional regulations, a *reglamento*, that clarifies and elaborates on the amendments.¹⁸⁶

The amendments explicitly only apply to people with a prognosis of less than six months, rather than to all people who require palliative care. In this respect, Mexico's law falls short of WHO's recommendation that people with life-limiting illnesses receive palliative care from the time of diagnosis.¹⁸⁷ As a result, as Mexican Supreme Court Justices José Ramon Cossío Díaz and José Fernando Franco González-Salas note in a recent article, people with a diagnosis of more than six months who suffer severe pain are "completely

¹⁸⁵ Article 166 Bis 13 of the health law. For a detailed analysis, see a publication by Supreme Court justices José Ramón Cossío Díaz and José Fernando Franco González-Salas et al in *Gaceta Médica de México*. José Ramón Cossío Díaz et al, *Regulación de los cuidados paliativos y muerte asistida (Regulation of palliative care and supported death)*, *Gaceta Médica de México* [in print].

¹⁸⁶ "Diario oficial mexicano," November 1, 2013, http://www.diputados.gob.mx/LeyesBiblio/regley/Reg_LGS_MPSAM_refo2_01nov13.doc (accessed on June 27, 2014).

¹⁸⁷ Under the WHO definition, palliative care should be provided not just to terminal patients but to all patients with life-limiting illnesses irrespective of their prognosis. WHO, "WHO Definition of Palliative Care," 2014, <http://www.who.int/cancer/palliative/definition/en/> (accessed on June 27, 2014).

unprotected.”¹⁸⁸ Mexico’s health law does establish that “integral treatment of pain” is a general objective of the health system, irrespective of diagnosis or prognosis and pain is defined broadly as including physical and mental pain.¹⁸⁹ However, the law does not provide any specifics on how this objective should be operationalized.¹⁹⁰

Table 5 - Rights Accorded to Persons in Terminal Stages of Illness under Mexico’s General Health Law

Access to Health Services	Right of Autonomy
Receive integral health services.	Receive clear, opportune and sufficient information about his illness and treatment options.
Be admitted to a health institution; Receive outpatient and inpatient attention.	Give informed consent in writing for the use or non-use of treatment, medicines or palliative care appropriate for his illness, needs and quality of life.
To leave voluntarily.	Assign a legal representative or person of confidence for in case the ability to express his wishes is lost.
To receive dignified, respectful and professional treatment that aims to preserve quality of life.	Formulate advanced directive which must be respected; revoke the advanced directive.
To request that the physician administers medicines to relieve pain.	Renounce, abandon, or refuse at any moment to receive or continue treatment considered extraordinary.
To choose to receive palliative care in a private home.	Voluntarily suspend curative treatment.
To receive spiritual care.	Request that curative care be re-initiated.

While the legislator left decisions on the specifics of the implementation of the amendments to the health ministry, the law sets out in broad terms a vision for integration of palliative care into the healthcare system, very much in line with Mexico’s international

¹⁸⁸ José Ramón Cossío Díaz et al., p. 6.

¹⁸⁹ Article 3 XXVII Bis.

¹⁹⁰ José Ramón Cossío Díaz et al., p. 11.

human rights obligations and the recommendations by WHO and WHA. Among others, the following broad obligations flow from the law:

- Palliative care must be integrated into the healthcare system. Health care providers have an obligation to offer palliative care to patients with terminal illness and a prognosis of six months of life or less;
- Healthcare institutions must ensure that staff are appropriately trained in the provision of palliative care;
- Medicines required in the provision of palliative care for treatment of pain and other symptoms must be available.

The amendments instructed the health ministry to issue the “regulations and official Mexican norms that are required to guarantee the exercise of the rights contained in this title” within 180 days.¹⁹¹ As noted, in December 2013, the ministry issued the regulations but the official norm (*Norma Oficial Mexicana*) has still not been issued. In absence of that norm, as Justices Cossío and Franco note, this is an “obstacle for the standardization of the services because the necessary parameters for clarifying what resources—human and material—a specialized palliative care unit requires are absent.”¹⁹² The publication of the official norm is expected in October 2014.¹⁹³

Obligation to Offer Palliative Care Services

The rights articulated in the law and regulation (see Table 5) are broad and sweeping enough that they can only be realized if all healthcare institutions in Mexico have personnel that offer palliative care. Indeed, the text of the palliative care chapter of the law suggests strongly that it requires all institutions of Mexico’s national healthcare system to offer this health service.

The law states, for example, that institutions of the national healthcare system “offer appropriate attention to patients with terminal illness” and “provide palliative care corresponding to the type and grade of the illness from the moment the terminal illness is

¹⁹¹ Diario Oficial of January 5, 2009.

¹⁹² José Ramón Cossío Díaz et al., p. 12.

¹⁹³ Human Rights Watch meeting with Dr. Sebastián García Saisó, director of the Department for Quality and Education in Health, Ministry of Health, September 4, 2014.

diagnosed until the last moment.”¹⁹⁴ The law does not provide for any exceptions or for mechanisms that would allow institutions that do not have palliative care to refer patients to healthcare institutions that do.

The law, however, is vague on how exactly healthcare institutions should offer palliative care, seeming to suggest a significant level of discretion on the part of the institutions. It states that institutions should “promote the creation of specialized areas that provide attention to patients with terminal illness.”¹⁹⁵ The regulation adds that healthcare institutions “shall have the infrastructure, suitable personnel, adequate material and technological resources for medical attention in palliative care in accordance with the level of complexity, the decision making power, the availability of financial resources, organization and functionality.”¹⁹⁶ In some places, the regulation appears less categorical than the law, referring to “institutions that provide these services.”¹⁹⁷ Both the law and regulation are silent on accountability for implementation of the legal requirements under the law.

The law and regulation furthermore do not address the role of primary care providers in palliative care, referring only to the obligations of specialists at secondary and tertiary care institutions in providing the service.¹⁹⁸ Primary care providers, however, will need to play an essential role in caring for patients who spend their last weeks or months at home. Justices Cossío and Franco comment that the focus in the legislation on secondary and tertiary level institutions is “not the most well-suited for opening access to these services as the patient has to move to these institutions” which normally are located only in major cities. They recommend considering that the legal context should “incentivize the participation of institutions of the primary level...This way, palliative care would be within reach of more people...”¹⁹⁹

¹⁹⁴ Article 166 Bis 13 (I and IV) of the health law. In accordance with article 50 of the health law, the national healthcare system includes public, social and private healthcare providers.

¹⁹⁵ Article 166 Bis 13 (V) of the health law.

¹⁹⁶ Article 138 Bis 12 of the 2013 regulation.

¹⁹⁷ Article 138 Bis 3, 138 Bis 12, 138 Bis 17 of the regulation.

¹⁹⁸ Article 166 Bis 15 of the health law.

¹⁹⁹ José Ramón Cossío Díaz et al., p. 12.

Home-based Palliative Care

Yes, it is possible to attend to a [dying] patient at home but only with good guidance. This would save the social insurance in care and cost. But they have to provide all that is needed to allow for care at home. – Adriana Lucía Preciado Santana²⁰⁰

The law states that patients with terminal illness have the right to “opt to receive palliative care in a private home,” an important right given that many people prefer to die in their own homes surrounded by relatives.²⁰¹ The law and regulation, however, are not clear on how exactly home-based palliative care is to be delivered and whether healthcare workers would visit the homes of patients who opt to exercise this right.

The relevant provisions of the law and regulation focus more on healthcare workers facilitating care at home than on actually providing the care. The law, for example, states that healthcare institutions must “[p]rovide services of orientation, advice and follow-up” to patients and their families if palliative care “is realized in a private home.”²⁰² The 2013 regulation specifies that as part of the palliative care plan, the treating physician must “consider those actions that need to be undertaken in the home of the patient in terminal stage by family members, caregivers or volunteers.”²⁰³ It also instructs members of the multidisciplinary palliative care team to offer “training to family members, caregivers and volunteers who will be in charge of attention and basic home care for the patient in terminal phase.”²⁰⁴

The law and regulation also oblige the ministry of health to put in place a free phone line to offer orientation, advice and follow-up to patients in terminal phase of illness, who opt to receive palliative care at home, as well as their family members or confidante.²⁰⁵ The

²⁰⁰ Human Rights Watch interview with Adriana Lucía Preciado Santana, February 22, 2012, Guadalajara.

²⁰¹ Article 166 Bis 3 (IX) of the health law.

²⁰² Article 166 Bis 13 (II) of the health law.

²⁰³ Article 138 Bis 15 of the 2013 regulation.

²⁰⁴ Ibid.

²⁰⁵ Article 166 Bis 13 (III) of the health law.

regulation adds that the health ministry must be “expeditious, attentive and respectful and sufficient to satisfy the needs for information of the person who calls.”²⁰⁶

In their article on the palliative care amendments, Justices Cossío and Franco call the right to opt for home-based palliative care “a significant challenge” for health care providers because it “requires realizing various activities outside the facilities where they normally work.” They also note that offering care at home is “an important step” in realizing the legislation’s objective to ensure people with a terminal illness can die in dignified conditions.²⁰⁷

Training of Healthcare Workers

The law and regulation clearly determine that health personnel must have adequate training in palliative care. The law holds, for example, that “treating physicians and the health team that offer palliative care...must be adequately trained humanly and technically by institutions authorized to do so.”²⁰⁸ To ensure such training the law stipulates that healthcare institutions must “guarantee the training and continued education of human resources in healthcare in the area of palliative care and attention to patients in terminal phase.”²⁰⁹ The regulation specifies that healthcare institutions must “seek to ensure that the training and continued education of professionals, technical, and auxiliary health staff in the area of palliative care is conducted at least once per year.”²¹⁰ Justice Cossío and Franco call the law’s provisions on training a “great challenge” as they require “availability of trained personnel throughout the republic.”²¹¹

The law, however, does not provide any guidance on what institutions and individuals are authorized to conduct such trainings, the contents of the trainings, or offer any accountability mechanisms. The law is furthermore silent on the integration of palliative

²⁰⁶ Article 138 Bis 16 of the 2013 regulation.

²⁰⁷ José Ramón Cossío Díaz et al., p. 7.

²⁰⁸ Article 166 Bis 14 of the health law.

²⁰⁹ Article 166 Bis 13 (VI) of the health law.

²¹⁰ Article 138 Bis 12 of the 2013 regulation.

²¹¹ José Ramón Cossío Díaz et al., p. 10.

care education into the curricula for students of medicine, nursing, psychology, and social worker—an essential step without which implementation of the law will fail.²¹²

Access to Medicines

Mexico’s health law and the regulation on palliative care clearly require that essential palliative care medicines be available and accessible. The 2013 regulation explicitly states that health institutions “must have a sufficient supply of pharmaceutical and supplies for the management of pain of the patient.”²¹³ The regulation does not determine what is considered a “sufficient supply.” These kinds of determinations are generally included in Mexico’s official norms.

²¹² México does not have a centralized system for certification of professionals, such as medical doctors and nurses. This complicates standard-setting in professional education as well as setting and enforcing requirements for continuing education.

²¹³ *Ibid.*

V. Making the Palliative Care Law Work

As long as there are no obligations and penalization the law remains nice words. The law is great but it does not oblige anyone to do anything...it is no more than a romantic notion – Dr. Guillermo Aréchiga, November 2011.²¹⁴

The adoption of the 2009 changes to Mexico's health law was a major step. With it, Mexico clearly determined that palliative care for terminal patients should be an integral part of the country's healthcare services. But putting the law in place was, in many ways, the easy part. Weaving palliative care into the DNA of Mexico's healthcare system is a challenge of a different magnitude. To achieve this, strong leadership by the federal and state governments and a comprehensive implementation strategy are essential.

It will require a persistent effort to adapt Mexico's healthcare system for the delivery of palliative care and to remove the barriers identified in this report that impede its provision. Government agencies, healthcare and health insurance providers, the pharmaceutical industry, civil society, academia and other players will need to work in coordination with each other to implement the systemic change required to make the vision of the law—that no one should have to die in unnecessary suffering—a reality. Without a clear plan of action and a coordinated effort, it is highly likely that palliative care will continue to develop in a haphazard and fragmented manner and that thousands of Mexicans will continue to suffer unnecessarily as a result.

The past year has seen increasingly positive signs that Mexico is ready to embrace this challenge. The years 2013 and 2014 have seen a major increase in attention for palliative care in Mexican society. Several Mexican civil society groups have taken up the issue as a priority while key high level government officials, including the health minister, the head of COFEPRIS and a Supreme Court justice, have all publicly underscored the importance of implementing the law. In October 2013, the Mexican Health Foundation and Tómatelo a Pecho organized an international seminar on palliative care in which key government officials, Mexican civil society leaders and international experts discussed the state of palliative care in the country and actions to be taken. The Mexican Health Foundation and

²¹⁴ Human Rights Watch interview with Dr. Guillermo Aréchiga, November 14, 2011, Guadalajara.

Tómatelo a Pecho, working closely with Harvard University, have since organized several follow-up meetings that included a broad range of actors to discuss specific next steps. At the same time, the National Autonomous University of Mexico has convened a number of meetings, initiated by former health secretary Juan Ramon de la Fuente, to discuss the training of healthcare personnel in palliative care as well as drug regulatory and other barriers to the use of opioid analgesics.

These various initiatives and meetings have yielded some important results. In November 2013, the ministry of health issued an important regulation clarifying a number of important normative issues the 2009 legal changes did not resolve.²¹⁵ In March 2014, COFEPRIS announced a decision to introduce an electronic system for licensing physicians to prescribe opioid analgesics, issuing barcoded stickers and keeping records.²¹⁶ That same month, Health Minister Mercedes Juan López instructed her ministry to develop a national palliative care strategy, asking Dr. Felicia Knaul of the Mexican Health Foundation to work with the ministry on this process.²¹⁷ Furthermore, the National Commission for Social Protection in Health, which administers one of Mexico's largest health insurers, Seguro Popular, added a number of key palliative care interventions to its package, which previously did not include palliative care for most patients. In mid-2014, the ministry of health tasked the department of quality and education in health with improving the availability of palliative care and hired an experienced palliative care physician to coordinate this work.²¹⁸ Following an internal review, the Mexican Social Security Institute recently announced its intention to strengthen availability of palliative care within its system, including psychosocial and spiritual support and access to medicines.²¹⁹ The adoption of the official norm on the implementation of the palliative care section of Mexico's health law is expected in October 2014. Moreover, the Public Health Council (Consejo Nacional de Salubridad) is preparing an agreement between different government agencies on the development of palliative care.

²¹⁵ Diario Oficial of January 5, 2009.

²¹⁶ For COFEPRIS' announcement, see: <http://t.co/DXLVO444PJ> (accessed June 27, 2014).

²¹⁷ A representative of the health ministry announced the decision to develop a national palliative care strategy at a consultation meeting on palliative care, organized by Fundación Mexicana para la Salud and Tómatelo a Pecho on June 20, 2014.

²¹⁸ Meeting with Dr. Eduardo González, deputy health minister, June 18, 2014, organized by Fundación Mexicana para la Salud and Tómatelo a Pecho; Meeting with Dr. Sebastián García Saisó, director of the department for quality and education in health, September 4, 2014.

²¹⁹ Email correspondence with the office of Dr. Javier Dávila, director of medical services México, October 13, 2014.

The implementation of the law will require a progression of actions that address several key challenges. First, the normative and conceptual basis for Mexico's palliative care system needs to be finalized. The law and regulation decide many big picture legal and conceptual questions but do not offer a specific model for the delivery of palliative care and leave a number of legal questions unresolved. Secondly, the healthcare system itself needs to be prepared to support and deliver palliative care services. This means that palliative care needs to be incorporated into insurance packages and financing structures and integrated into educational programs for healthcare workers. Finally, Mexico will need to build the delivery system for palliative care by setting up services, training existing healthcare workers, and creating referral systems.

Finalizing the Normative and Conceptual Base

The chapter in the health law and the 2013 regulations offer a partial normative framework and set out a broad vision of universal palliative care for patients with terminal illness. However, as noted above, the law and regulation also leave a number of major conceptual and normative questions unresolved. It is essential that the government, in cooperation with the national health system, civil society, and other relevant actors, address these conceptual and normative gaps to allow for proper operationalization and implementation of an integrated palliative care system. The official norm will be essential in this respect, as is the national palliative care strategy the health ministry is currently developing.

Choosing Model(s) of Delivery. The law and regulation are not specific on the model of palliative care that should be used, leaving that decision to the ministry of health. The law and regulation do set some parameters that the model must meet including the ability to: grant patients a right to opt to receive palliative care in their homes; determine that all healthcare institutions must offer palliative care; articulate a number of specific obligations for healthcare workers of secondary and tertiary care institutions; and determine that palliative care must be provided by multidisciplinary teams on the basis of a palliative care treatment plan. Different models of palliative care may meet these criteria. The official norm and national strategy should address in particular how home-based palliative care will be delivered, what role primary care providers will play, and lay the groundwork for a functioning referral and counter-referral system.

- **Role of primary health providers.** The law and regulation make no specific mention of primary health providers or their involvement in the delivery of palliative care. In order to ensure that palliative care is offered as close to the home of the patient as possible, an active role for primary health teams is essential. The government thus has to determine what role these healthcare workers are to play and how they are going to be trained and supported. Effective coordination and cooperation between primary health providers and the multidisciplinary palliative care teams at secondary and tertiary care facilities that are mandated by the law will likely be essential to the successful implementation of a palliative care system.
- **Home-based palliative care.** The law states that patients with terminal illness have the right to “opt to receive palliative care in a private home” but it offers little guidance on how home-based palliative care is to be delivered apart from instructing healthcare workers to train family members in basic care needs. In order to ensure effective home-based palliative care, home visits by trained healthcare workers for certain groups of patients are essential. The government needs to determine who would conduct such visits, who would be eligible for home care visits, and ensure the regulations permit home-care teams to carry essential palliative care medicines, including opioid analgesics. It will also have to develop a system for round-the-clock support for patients at home and their families, via telephone, text message and/or video link. Health insurance policies should cover these interventions. The national phone number the law envisions is unlikely to work effectively unless patients and families can access on-call healthcare workers who have access to their files and know their specific situations.
- **Referral and counter-referral systems.** In order to allow patients to receive highest quality palliative care as close to home as possible, it is essential that a strong system of referral and counter-referral be developed. As discussed above, most patients with life-limiting illnesses receive curative treatment at tertiary or secondary care facilities that are far from their homes. A system needs to be put in place that allows patients to be referred between levels of care so that they can

receive palliative care close to home while primary care providers can also refer them back to higher level facilities if so required.

- **Palliative care for children.** The law refers to pediatric palliative care only in passing, making it clear that children with terminal illness have a right to this health service without providing any detailed guidance. The palliative care needs of children differ significantly from those of adults as do the skills required by healthcare workers, making it important to develop specific child-friendly models for them. These models should address the special needs of children, their parents and siblings in terms of communication about the illness, psychosocial needs, assessment of pain, and the place of care.

Panama's National Palliative Care Strategy

As in Mexico, Panamanian law grants patients a right to receive palliative care.²²⁰ It requires all hospitals to have palliative care units and charges primary health centers with providing palliative care to patients who require it over extended periods of time. In 2011, Panama's health ministry adopted a national palliative care strategy to help implement the law.²²¹

The philosophy behind the strategy is that patients should always receive care as close to home as possible. It sets out a model that links the different levels of the healthcare system so that patients can move easily between them depending on their situation. A patient in curative treatment may receive palliative care at the national cancer institute but once they are no longer curable they are referred to care by their primary care providers. Conversely, a palliative patient with complex symptoms that primary health centers are unable to control can be referred to secondary or tertiary levels of care.

A key role in this model is assigned to Panama's regional hospitals, all of which must

²²⁰ See article 23 of Law 68 of November 20, 2003, available at: <http://www.gorgas.gob.pa/?wpdmdl=2126&ind=1> (accessed July 9, 2014).

²²¹ Ministerio de Salud de Panamá, "National Palliative Care Program (Programa Nacional de Cuidados Paliativos)," 2011, [http://190.34.154.93/mcp/sites/all/files/Cuidados%20paliativos%20\(2\).pdf](http://190.34.154.93/mcp/sites/all/files/Cuidados%20paliativos%20(2).pdf) (accessed July 9, 2014).

have multidisciplinary palliative care teams. These teams not only offer clinical care but are also responsible for training healthcare workers at the primary level of care; offering them ongoing support in the care for patients; and working with nongovernmental groups, such as NGOs and churches, to develop community support for palliative care. The multidisciplinary teams are also the link between the different levels of care, facilitating referrals up and down the chain.

Overall responsibility for the implementation of the strategy lies with the health ministry, which hired a national palliative care coordinator for the purpose. The coordinator works closely with a national palliative care commission which consists of all the principal players: the social security agency, the University of Panama, the national cancer institute, the children's hospital and Panama's main hospice and palliative care association.

Panama has made significant progress with the implementation of this strategy. Each of the country's regions has a palliative care coordinator and more than half of the regions have active palliative care programs. The number of patients receiving palliative care has risen steadily, from around 1,000 in 2010 to 2,500 in 2013. Even so, challenges remain, especially in remote regions, within the social security system and in the provision of palliative care to children.²²²

Mandating Inclusion of Palliative Care in Insurance Packages. While the law and regulation clearly identify palliative care as a right of patients with terminal illness, both are silent on the role of insurance providers. The explicit inclusion of palliative care interventions, medicines and other medical products in insurance packages will be essential to their availability and financial accessibility. The normative framework should clearly require health insurers to cover palliative care and associated institutions to offer it or otherwise facilitate access to it.

Ensuring Inclusion of Patients with Prognosis Exceeding Six Months. The palliative care chapter of the health law explicitly leaves people with life-limiting illnesses who are not terminal unprotected even if they do require palliative care. The WHO definition of

²²² Email correspondence with Dr. Gaspar Da Costa, Panama's national palliative care coordinator, September 10, 2014.

palliative care does not contain any reference to life expectancy, instead focusing on patient need, and international human rights law grants people a right to appropriate health services to all. The government will thus need to determine how the healthcare system should address the palliative care needs of these patients.

The limited prognosis requirement of the law is particularly problematic for pediatric palliative care. A life-limiting illness in a child has great impact on parents and siblings, making early initiation of care focused on quality of life care especially important. Furthermore, many children who require palliative care have neurological diseases, genetic conditions, congenital malformations, or degenerative disorders that undermine the quality of life of the child and the whole family over periods of time far beyond six months.

Ensuring Access to Medicines. Changes to the normative base are finally required to ensure that home-based palliative care teams can carry these medicines on visits to patients. The government should use the WHO policy guidelines “Ensuring balance in national policies on controlled substance. Guidance for availability and accessibility of controlled medicines” in making these changes.²²³

Preparing the Healthcare System for the Integration of Palliative Care

As palliative care has traditionally not been part of Mexico’s healthcare system, a series of steps are required to ensure the building blocks for the delivery system are in place. Without adequate human resources, clinical protocols, availability of medicines, and other medical products and coverage by insurance providers, it will be impossible to build an effective and sustainable delivery system for palliative care. Thus, the government needs to prepare the system for the integration of palliative care, working with the healthcare institutions, health insurers, academia and other training institutes for healthcare workers, and civil society groups.

Incorporating Palliative Care into Health Insurance Systems. In addition to introducing normative rules that require health insurers to cover palliative care, steps need to be taken to actually integrate palliative care interventions, and medicines into existing insurance

²²³ WHO, “Ensuring Balance in National Policies on Controlled Substance: Guidance for Availability and Accessibility of Controlled Medicines,” http://whqlibdoc.who.int/publications/2011/9789241564175_eng.pdf?ua=1.

packages and medicines lists. This includes revising Seguro Popular's list of covered interventions to include palliative care and the medicines lists of Seguro Popular and IMSS. Given their importance in provision of home-based palliative care, all insurance providers should also ensure that home visits and consults by phone or video are adequately covered.

Preparing Human Resources. The single greatest challenge is the preparation of adequate personnel to deliver palliative care. As noted above, very few healthcare workers are currently trained in this area. Most undergraduate training for health providers does not include any palliative care; availability of in-service training is very limited; and there are few continued education programs in palliative care.

Making palliative care an integral part of health services offered in Mexico requires that all healthcare workers have at least basic knowledge of and skills in palliative care. This requires a systematic effort to train existing healthcare workers and to ensure that healthcare workers currently in pre-service training learn about palliative care during academic programs and as part of in-service training.

We recommend that government undertake the following steps:

- Work with associations of medical, nursing, pharmacy, psychology and social work faculties to ensure palliative care training is incorporated into relevant **undergraduate curricula** as a mandatory subject.
- Work with academic hospitals to ensure that **rotations in palliative care** units and pain clinics become a standard element of residencies of healthcare workers, including for pediatricians in training.
- Integrate palliative care training into **continuing education programs** for healthcare workers, including training in children's palliative care. To allow a major scale-up of palliative care, all current healthcare workers need training in the basics of palliative care. A plan should be drawn up to use continuing education to bring such training to all healthcare workers, including those at children's

hospitals, within the next few years, with a special focus on primary healthcare workers.

- Recognize palliative care as a **specialty/subspecialty of medicine**. Recognition of palliative care as a (sub)specialty of medicine will accelerate training of healthcare workers and encourage academic research.
- Recognize at least one hospital with a successful palliative care service in each state as a **training site** and invest in the capacity of these hospitals to conduct training activities.

Training Primary Care Providers in Panama

Under Panama’s national palliative care program, a major investment was made into training of healthcare providers, with an emphasis on primary care givers. The program envisioned training and mentoring primary care givers over an extended period of time to gradually develop their ability to offer palliative care:

It is expected that the degree of training of healthcare personnel will increase with time and that accordingly, they will be able to offer more complex care at each level of attention so that the need to refer patients from one level to the next is reduced.²²⁴

The program identified different competencies healthcare providers should have after receiving different levels of training.

Training Levels	Competencies
No training	Identify and register cases of palliative care need and conduct visits every two weeks.
Basic training	Ability to develop an initial treatment and nursing plan, and to treat light symptoms and attend to patients in their final hours.
Intermediate training	Treatment of moderate symptoms; offering subcutaneous treatments; treat ulcers; and prevention of caregiver burn-out or taking steps when no caregiver is available.
Advanced training	Treatment of severe symptoms; administration of intermittent sedation; address psychological distress and monitoring of quality of life.

²²⁴ National Palliative Care Program of Panama, p. 25.

The primary responsibility for training healthcare staff at the primary level lies with palliative care teams established in secondary level hospitals in each of Panama's regions through programs of continuing education and hands-on mentorship of primary care givers.

Under the program, a number of modules were developed for basic, intermediate and advanced training of current healthcare workers as well as government officials. Trainings were conducted both in-person and online. In total, more than 1200 people in Panama have received training in palliative care.²²⁵

Medicines Availability. The government and insurance providers need to ensure that all essential medicines for palliative care for adults and children in all relevant formulations and dosages, as defined by the WHO, are included in the medicines lists of the Public Health Council and insurance providers. All these medicines should be approved for use at all levels of care and covered by insurance plans. The lists should follow the WHO Model List of Essential Medicines in grouping all essential palliative care medicines together in a section on pain and palliative care.

Controlled Medicines. Ensuring availability and accessibility of controlled medicines, especially opioid analgesics, at all levels of care will be essential for the delivery of palliative care. Steps to improve their availability and accessibility should focus on drastically increasing the number of physicians that prescribe these medicines and pharmacies that dispense them and on resolving existing difficulties with prescribing and dispensing them.

The ministry of health and COFEPRIS have already announced the introduction of an electronic system for issuing prescribing licenses and barcoded stickers to physicians, and for keeping records at pharmacies.²²⁶ The planned system has the potential for resolving many of the problems with licensing and barcoded stickers that currently exist.

²²⁵ Email correspondence with Dr. Gaspar Da Costa, Panama's national palliative care coordinator, September 10, 2014.

²²⁶ Announcement of the ministry of health and COFEPRIS of March 28, 2014, available at: <http://t.co/DXLVO444PJ> (accessed June 27, 2014).

A digital system could also lead to new barriers to prescribing these medicines, which will need to be avoided or addressed. Some of these are:

- **Avoid application fees or requirement to buy specific software or equipment.** This would be a deterrent for many physicians and would likely result in limited numbers of prescribers.
- **Ensure system functions even in areas with frequent power outages and unstable or slow internet connections.** It will be critical that the digital system can function well under varying conditions.
- **Address facilities without, or with limited internet access.** There are many small health facilities in Mexico that currently do not have internet.

The government has already announced that it would remove the requirement that **physicians' private addresses** be included in prescription forms. It should finalize this step as soon as possible. Finally, the government should facilitate an uninterrupted and adequate supply of opioid analgesics, using the International Narcotics Control Board and WHO's guide on estimates requirements for controlled medicines,²²⁷ and encourage the **production of generic opioid analgesics** which would both help keep down the cost of these medicines and help prevent stock-outs.

Clinical Guidance. The Centro Nacional de Excelencia Tecnológica en Salud (CENETEC), in cooperation with IMSS, issued a guide on clinical practice and a quick reference guide on palliative care in 2011.²²⁸ We recommend that the ministry of health and CENETEC ensure wide distribution of this clinical guidance as part of efforts to train healthcare workers and establish palliative care services. They should also convene periodic meetings of palliative care providers, primary care providers, and other relevant parties to review and update this clinical guidance. Clinical guidance needs to be developed for pediatric palliative care,

²²⁷ INCB and WHO, "Guide on Estimating Requirements for Substances under International Control," 2012, http://www.incb.org/documents/Narcotic-Drugs/Guidelines/estimating_requirements/NAR_Guide_on_Estimating_EN_Ebook.pdf (accessed July 15, 2014).

²²⁸ The clinical guide can be found at: http://www.cenetec.salud.gob.mx/descargas/gpc/CatálogoMaestro/445_GPC_Cuidados_paliativos/GER_Cuidados_Paliativos1x.pdf (accessed June 27, 2014). The quick reference guide can be found at: http://www.cenetec.salud.gob.mx/descargas/gpc/CatálogoMaestro/445_GPC_Cuidados_paliativos/GRR_cuidadospaliativos_4072011x2x.pdf (accessed June 27, 2014).

taking into consideration the 2012 WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses.²²⁹

Paving Way for Home-Based Palliative Care. Once conceptual questions around home-based palliative care have been decided, steps will need to be taken to set up home-based palliative care teams, to ensure they can prescribe all essential palliative care and that home visits and phone or video consults are covered by insurance providers.

Research and Data Collection. An investment should be made in research into the need for palliative care among adults and children and across different illnesses; availability and accessibility of palliative care; the effectiveness and efficiency of available services; and specific models of delivery. Such research will allow the government and health system to assess progress and make adjustments to policy or delivery systems as needed. We recommend, among others, the following steps:

- Mexico should use the consumption of opioid analgesics per cancer death as an indicator to measure progress in the development of palliative care over time, as recommended by the WHO Global Action Plan on the Prevention and Control of NCDs.²³⁰
- The Asociación Latinoamericana de Cuidados Paliativos has developed a set of indicators for assessing the availability of palliative care that measure progress in policy development, education, and drug availability.²³¹ Using these indicators, Mexico could set a baseline and measure progress.
- Hospitals should be required to report regularly on the availability of pain clinics and palliative care. These units/services should be included in organograms of hospitals.

²²⁹ WHO, “WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses,” http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf.

²³⁰ WHO, “WHO Global Action Plan on the Prevention and Control of Non Communicable Diseases for 2013-2020,” 2014, http://www.who.int/nmh/events/ncd_action_plan/en/ (accessed on June 27, 2014).

²³¹ Asociación Latinoamericana de Cuidados Paliativos, “Palliative Care Indicators 2013,” 2013, [http://cuidadospaliativos.org/uploads/2013/3/Palliative%20Care%20Indicators%20ALCP%20\(english\).pdf](http://cuidadospaliativos.org/uploads/2013/3/Palliative%20Care%20Indicators%20ALCP%20(english).pdf) (accessed on June 27, 2014).

Building the Delivery System

Putting in place the delivery system for palliative care will undoubtedly be the most challenging part of implementing the law. As noted above, at present the number of palliative care services in Mexico is very limited and few healthcare workers have any training in the discipline, making it impossible to establish high quality palliative care services throughout the country and at all levels of care overnight. This will have to be a gradual process.

It is, however, critical that the government show a strong commitment and strong leadership to initiate this process and keep it moving. Given the complexity of the task and the number of players involved it is essential that Mexico develop a mandatory implementation plan that assigns clear responsibilities and timelines, and includes accountability mechanisms.

Palliative Care in Mexico State

In 2009, Mexico State, then led by Mexico's current president, Enrique Peña Nieto, launched a state palliative care program with the objective of developing palliative care units in hospitals in all districts of the state, and training primary healthcare workers in supporting patients requiring palliative care.²³² The state's health ministry, headed by Gabriel O'Shea, who now leads the National Commission on Social Protection in Health, hired a palliative care coordinator and assigned budget to develop a series of training and promotion activities. The state government also included palliative care in its development plan for 2011 to 2017 as part of its objective to improve the care for older persons and people with non-communicable diseases.

By mid-2014, nine public hospitals in seven of the state's 18 districts had opened palliative care units, including the state's children's hospital. Previously, palliative care was available only in one hospital in Toluca, the state capital. Each unit offers both hospital-based care to inpatients and outpatients and home care for patients

²³² Information in this text box is based on communication with Dr. Celina Castañeda, who was appointed as the state's palliative care coordinator in 2009 and currently works in the subdivision for planning of the National Commission for Social Protection in Health.

whose condition no longer permits them to come to the hospital. State officials expect to open palliative care units in hospitals in the remaining 11 districts by 2016.

The program has also trained nurses from all public health clinics and hospitals in the state, a total of about 3,600 people, on principles of and basic skills in palliative care. Furthermore, it has worked with the National Polytechnic Institute and the Autonomous University of Mexico State to establish four diploma courses in palliative care for doctors, nurses, psychologists and social workers.

The specifics of such plan will necessarily depend on decisions made regarding the normative and conceptual framework and the model(s) of care Mexico decides to implement. However, we believe that there are a number of key criteria the plan must fulfill in order to be effective. These include the following:

- The national plan should set the **overall strategy** for the development of the delivery system. Each state should develop a **specific state-level strategy** that takes into account the specific circumstances of the state. Great variation between circumstances of different states and current development of palliative care services requires that implementation strategies are tailored.
- The national and state plans should clearly **identify the responsibilities of different institutions** involved, including the state health department, health insurers, healthcare providers, and other relevant institutions.
- The plans should establish **specific targets and benchmarks** against which progress can be measured. These should include targets and benchmarks for training of healthcare workers, establishment of multidisciplinary teams and palliative services, and on provision of palliative care at primary care level and at home.
- The plans should establish **strong accountability mechanisms**. The health ministry and state departments of health should have final responsibility for

implementation of the strategies and be required to report on a regular basis on progress made. The plans should grant the health ministry and health departments tools to impose sanctions, if needed, on institutions that are not complying with the implementation plan or law. We recommend that at the national and state levels specific officials are put in charge of the implementation plans.

- The plans should make **resources** available for the implementation process.
- **Training of existing healthcare personnel** should be one of the central components of the implementation plans. Training programs should, whenever possible, include classroom and bedside teaching; rotations into palliative care services; and mentoring. Training is likely to require the most significant resource investment.
- The implementation strategies should **build on existing palliative care services** in each state. These services should play a key role in the training of healthcare providers, including through rotations and bedside teaching, setting up palliative care services at secondary and tertiary hospitals, and in putting together multidisciplinary palliative care teams.
- The plans should include a clear strategy for **integrating palliative care into primary care**. This will require multidisciplinary palliative care teams at secondary level hospitals to support primary care providers, including a mentoring and referral system.

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Appendix 1: Public Hospitals with Known Palliative Care Services in Mexico

In black: Palliative care services
In red: Pain clinic but no palliative care

SSA: Ministry of Health
IMSS: Mexican Social Security Institute
ISSSTE: Institute of Security and Social Services for Employees of the State

STATE	MUNICIPALITY	HOSPITAL	PROVIDER
Aguascalientes	Aguascalientes	Hospital General Miguel Hidalgo	SSA
	Aguascalientes	Hospital General de Zona N°1	IMSS
	Aguascalientes	Hospital General Calvillo	SSA
	Aguascalientes	Hospital Tercer Milenio	SSA
Baja California	Mexicali	Hospital General	SSA
	Mexicali	Unidad de Especialidades Médicas de Oncología (UNEME)	SSA
Baja California Sur	La Paz	Centro Estatal de Oncología Dr. Rubén Cardoza Macías	SSA
	La Paz	Unidad Médica de Atención Ambulatoria La Paz (UMAA)	IMSS
Campeche	Campeche	Centro Estatal de Oncología de Campeche	SSA
Coahuila	Saltillo	Hospital Universitario Dr. Gonzalo Valdés	State University
Colima	Colima	Centro Estatal de Cancerología de Colima	SSA
	Colima	Hospital Regional Universitario	University
Chiapas	Tuxtla Gutiérrez	Hospital ISSTECH	ISSTECH
	Tuxtla Gutiérrez	Hospital Regional Dr. Rafael Pascacio Gamboa,	SSA
Chihuahua	Chihuahua	Hospital de Pensionados	ISSSTE
	Chihuahua	Centro Estatal de Cancerología Chihuahua	SSA
Distrito Federal	Benito Juárez	Hospital 20 de Noviembre	ISSSTE
	Coyacán	Instituto Nacional de Pediatría	SSA
	Cuauhtémoc	Hospital de Oncología Centro Médico Nacional Siglo XXI	IMSS
	Cuauhtémoc	Hospital General de Mexico Dr. Eduardo Liceaga	SSA
	Cuauhtémoc	Hospital Infantil de México Dr. Federico Gómez	SSA
	Gustavo Madero	Hospital 10. de Octubre	ISSSTE
	Álvaro Obregon	Hospital Regional Lic. Adolfo López Mateos	ISSSTE
	Tlalpan	Instituto Nacional de Cancerología	SSA
	Tlalpan	Instituto Nacional de Neurología	SSA
	Tlalpan	Instituto Nacional de Cardiología	SSA
	Tlalpan	Instituto Nacional de Ciencias Médicas y Nutrición Salvador Zubirán	SSA
	Tlalpan	Instituto Nacional de Enfermedades Respiratorias	SSA
	Tlalpan	Instituto Nacional de Rehabilitación	SSA
	Tlalpan	Hospital General Dr. Manuel Gea González	SSA
	Durango	Durango	Centro Estatal de Cancerología de Durango
Durango		Hospital General 450	SSA
Durango		Hospital General de Zona con Medicina Familiar (HGZMF) 1	IMSS
Durango		Clínica Santiago Ramón y Cajal	ISSSTE
Guanajuato	Celaya	Hospital General Celaya	SSA
	León	Hospital Regional de Alta Especialidad del Bajío	SSA
	León	Hospital General Regional de León	ISSSTE
	León	Unidad Médica de Atención Especializada (UMAE) T1 León	IMSS
	San Miguel Allende	Hospital General de San Miguel Allende	SSA
GUERRERO			
Hidalgo	Pachuca	Hospital General Pachuca	SSA
Jalisco	Guadalajara	Instituto Jalisciense de Cancerología	SSA
	Guadalajara	Hospital Civil Juan I. Menchaca	SSA
	Zapopan	Instituto Jalisciense de Cuidados Paliativos y Alivio al Dolor (PALIA)	SSA
	Zapopan	Hospital General de Occidente	SSA

STATE	MUNICIPALITY	HOSPITAL	PROVIDER
Jalisco	Zapopan	Hospital Regional Valentín Gómez Farías	ISSSTE
	Guadalajara	Hospital Civil Fray Antonio Alcalde	SSA
	Guadalajara	Centro Médico de Occidente	IMSS
Mexico State	Acolman	Hospital para Enfermos Crónicos Tepexpan Gustavo Baz Prada	SSA
	Cuautitlán	Hospital General de Cuautitlán José Vicente Villada	SSA
	Ecatepec	Hospital General Ecatepec José María Rodríguez	SSA
	Naucalpan	Hospital Maximiliano Ruiz Castañeda	SSA
	Nezahualcóyotl	Hospital La Perla	SSA
	Tlalnepanta	Hospital General Valle Ceylán	SSA
	Toluca	Hospital de General Dr. Nicolás San Juan	SSA
	Toluca	Hospital para el Niño IMIEM	State
	Toluca	Centro Oncológico Estatal del ISSEMYM	State
	Toluca	Centro Médico "Lic. Adolfo López Mateos"	SSA
Michoacán	Morelia	Centro Estatal de Atención Oncológica de Morelia	SSA
	Morelia	Hospital Dr. Miguel Silva	SSA
Morelos	Cuernavaca	Hospital General Cuernavaca Dr. José G. Parres (Clínica de Algología)	SSA
	Emiliano Zapata	Hospital de Alta Especialidad Centenario de la Revolución Mexicana	ISSSTE
	Emiliano Zapata	Hospital del Niño Morelense	SSA
	Cuernavaca	Hospital General Regional 1	IMSS
Nayarit	Tepic	Centro Estatal de Cancerología de Nayarit	SSA
	Tepic	Hospital Civil Dr. Antonio González Guevara	SSA
	Ixtlan del Rio	Hospital Integral de Ixtlan del Rio	SSA
Nuevo León	Monterrey	Hospital Universitario Dr. José Eleuterio González	State University
	Monterrey	Hospital de Traumatología y Ortopedia 21	IMSS
	Monterrey	Hospital de Cardiología 34	IMSS
	Monterrey	Hospital Regional de Especialidades 25	IMSS
	Sabinas Hidalgo	Hospital General Virginia Ayala de Garza	SSA
	San Nicolás de Los Garza	Hospital Metropolitano Dr. Bernardo Sepúlveda	SSA
Oaxaca	Oaxaca	Centro de Oncología y Radioterapia de Oaxaca	SSA
	Oaxaca	Hospital General "Dr. Aurelio Valdivieso"	
	San Bartolo Coyotepec	Hospital Regional de Alta Especialidad del Estado de Oaxaca	SSA
Puebla	Puebla	Hospital Universitario Universidad Autónoma de Puebla	State University
	Puebla	Hospital Regional	ISSSTE
Querétaro	Querétaro	Hospital General de Querétaro	SSA
	Querétaro	Hospital de Especialidades del Niño y la Mujer Felipe Núñez L.	SSA
Quintana Roo	Benito Juárez	Hospital General de Cancún Jesús Kumate Rodríguez	SSA
San Luis Potosí	San Luis Potosí	Hospital Universitario de San Luis (Hospital Central Dr. Ignacio Morones Prieto)	SSA
Sinaloa	Culiacán	Hospital General de Culiacán	SSA
	Culiacán	Instituto Sinaloense de Cancerología	SSA
	Culiacán	Manuel Cardenas de la Vega	ISSSTE
Sonora	Hermosillo	Hospital Oncológico del Estado de Sonora	SSA
Tabasco	Centro (Villahermosa)	Hospital de Alta Especialidad Dr. Juan Graham Casasús	SSA
	Centro (Villahermosa)	Hospital Dr. Daniel Gurria Urgell	ISSSTE
	Centro (Villahermosa)	Hospital ISSET Dr. Julián Manzur Ocaña	State
	Centro (Villahermosa)	Hospital Regional de Alta Especialidad Dr. Gustavo A. Roviroza Pérez	SSA
Tamaulipas	Tampico	Hospital General de Tampico Dr. Carlos Canseco	SSA
	Victoria	Hospital General Victoria Dr. Norberto Treviño Zapata	SSA
	Reynosa	Hospital General de Zona 15 Reynosa	IMSS
	Ciudad Madero	Hospital General Regional 6 Cd. Madero	IMSS
	Victoria	Unidad de Especialidades Médicas (UNEME) Centro Oncológico de Tamaulipas	SSA
TLAXCALA			
Veracruz	Xalapa	Clinica Hospital Xalapa	ISSSTE
	Veracruz	Hospital Regional de Alta Especialidad de Veracruz	SSA
	Xalapa	Centro Estatal de Cancerología Dr. Miguel Dorantes Mesa	SSA
	Veracruz	Centro Médico Nacional Adolfo Ruiz Cortines	IMSS
Yucatán	Mérida	Hospital Regional de Alta Especialidad de la Península de Yucatán	SSA
Zacatecas	Zacatecas	Hospital General de Zona	IMSS

Appendix 2: Comparison of WHO Essential Medicines List with Mexican Lists

WHO LIST	FORMULATION AND DOSE	PUBLIC HEALTH COUNCIL	
		Basic List	List for 2nd and 3rd level
Acetylsalicylic Acid	Tablet: 100 mg to 500 mg.	500mg	
	Suppository: 50 mg to 150 mg.		
Ibuprofen	Tablet: 200 mg; 400 mg; 600 mg.	Metamizol 500mg	
	Oral Liquid: 200 mg/5 ml.		
Paracetamol	Tablet: 100 mg to 500 mg.	500mg	
	Oral Liquid: 125 mg/5 ml.	100mg/ml	
	Suppository: 100 mg.	300,100mg	
Codeine	Tablet: 30 mg (phosphate).		Tramadol Tablet 37.5-325mg, Injectable 100mg
Morphine	Injection: 10 mg (morphine hydrochloride or morphine sulphate) in 1ml ampoules.		2,5mg/2,5ml,10mg, 50mg/2ml
	Oral Liquid: 10 mg (morphine hydrochloride or morphine sulphate)/5 ml.		
	Tablet (immediate-release): 10 mg (morphine sulphate).		30mg
	Tablet (slow release): 10 mg-200 mg (morphine hydrochloride or morphine sulphate)*.		100mg, 60mg*
	Granules (slow release; to mix with water): 20 mg to 200 mg (morphine sulphate).		
Amitriptyline	Tablet: 10 mg; 25 mg; 75 mg.	25mg	
Cyclizine	Injection: 50 mg/ml.		
	Tablet: 50 mg.		
Dexamethasone	Injection: 4 mg/ml in 1ml vials (disodium phosphate).	8mg/2ml	
	Oral Liquid: 2 mg/5 ml.		
	Tablet: 2 mg [c]; 4 mg.	.5mg	
Diazepam	Injection: 5 mg/ml.		10mg/2ml
	Oral Liquid: 2 mg/5 ml.		5ml
Diazepam, cont'd	Rectal Solution:2.5mg; 5mg; 10g.		
	Tablet: 5mg; 10 mg		10mg
Docusate Sodium	Capsules: 100 mg.		
	Oral Liquid: 50 mg/5 ml.		
Fluoxetine	Solid Oral Dosage Form: 20 mg (as hydrochloride).	20mg	

IMSS MEDICINES LIST	SEGURO POPULAR LIST	
	Basic Medicines List	List of Fund for Catastrophic Expenses
500mg	500mg, 300mg	500mg, 300mg
Metamizol 500mg Injectable Sol. 1 g/ 2 ml	Metamizol 500mg Injectable Sol. 1 g/ 2 ml	Metamizol Injectable Sol. 1 g/2 ml
500mg	500mg	500mg
100mg/ml	100mg/ml	
300mg	100mg, 300mg	
Tramadol Tablet 37.5-325mg, Injectable 100mg	Tramadol Tablet 37.5-325mg, Injectable 100mg	Tramadol Injectable Solution 100 mg/2 ml
2,5mg/2,5ml, 10mg, 50mg/2ml	2,5mg/2,5ml	2,5mg, 50mg, 10mg
		30mg
100mg, 60mg, 30mg*		100, 60mg*
25mg	25mg	25mg
8mg/2ml	8mg/2ml	8mg/2ml
.5mg	.5mg	.5mg
10mg/2ml	10mg/2ml	
10mg	10mg	
20mg	20mg	

- First Level
- First and Second Level
- Second and Tertiary Level
- Tertiary Level
- No Distinction
- Completely Lacking

** Included in the Mexican medicines list, but is not available in Mexico.

WHO LIST	FORMULATION AND DOSE	PUBLIC HEALTH COUNCIL	
		Basic List	List for 2nd and 3rd level
Haloperidol	Injection: 5 mg in 1ml vial.		5mg/ml, 50mg/ml
	Oral Liquid: 2 mg/ml.		2mg
	Solid Oral Dosage Form: 0.5 mg; 2mg;		5mg
Hyoscine Butylbromide	Injection: 20 mg/ml.	Injectable 20mg, tablet 10mg	
Hyoscine Hydrobromide	Injection: 400 micrograms/ml; 600 micrograms/ml.		
	Transdermal Patches: 1 mg/72 horas.		
Lactulose	Oral Liquid: 3.1 3.7 g/5 ml.	Psyllium Powder 49.7 g/100 g	
Loperamide	Solid Oral Dosage Form: 2 mg.	2mg	
Metoclopramide	Injection: 5 mg (hydrochloride)/ml in 2ml vial.	10mg/2ml	
	Solid Oral Form: 10 mg (hydrochloride)	10mg	
	Oral Liquid: 5 mg/5 ml.	4mg	
Midazolam	Injection: 1 mg/ml; 5 mg/ml.		5mg/5ml, 15mg/3ml
	Oral Liquid: 2mg/ml [c].		
	Solid Oral Dosage Form: 7.5 mg; 15 mg.		7.5mg
Ondansetron	Injection: 2mg base/ml in 2ml ampoule (as hydrochloride).		8mg/4ml
	Oral Liquid: 4 mg base/5 ml.		
	Solid Oral Dosage Form: 4 mg base/8 mg. Base		8mg
Senna	Oral Liquid: 7.5 mg/5 ml.	Oral s. 200 mg/100 ml Granulated 54.2 g/300 mg/100 g Tablet 8.6	

IMSS MEDICINES LIST	SEGURO POPULAR LIST	
	Basic Medicines List	List of Fund for Catastrophic Expenses
5mg/ml, 50mg/ml	5mg/ml, 50mg/ml	
2mg		
5mg	5mg	
Injectable 20mg/m, tablet 10mg	Injectable 20mg/m, 10mg/m tablet 10mg	
Psyllium Powder 49.7 g/100 g	Psyllium Powder 49.7 g/400 g	
2mg	2mg	2mg
10mg/2ml	10mg/2ml	10mg/2ml
10mg	10mg	10mg
4mg/ml	4mg/ml	
15mg/3ml	5mg/5ml, 15mg/3ml, 50mg/10ml	
8mg/4ml	8mg/4ml	8mg/4ml
8mg		
200 mg/100 ml	Oral Solution 200 mg/75 ml Tablet 8.6 mg 20 tablets	

- First Level
- First and Second Level
- Second and Tertiary Level
- Tertiary Level
- No Distinction
- Completely Lacking

** Included in the Mexican medicines list, but is not available in Mexico.

CARE WHEN THERE IS NO CURE

Ensuring the Right to Palliative Care in Mexico

Every year, tens of thousands of people in Mexico develop debilitating symptoms, such as pain, breathlessness and anxiety, due to cancer, HIV/ AIDS, and other life-threatening health conditions. Although Mexico's health law grants these people a right to palliative care, only a few dozen public healthcare institutions across the country actually offer this health service. Most healthcare personnel have received no training in the discipline, and few doctors are licensed to prescribe strong pain medicines that are essential for palliative care. Consequently, many patients cannot realize their legal right to adequate treatment and face great and unnecessary suffering.

"Care When There Is No Cure" identifies the challenges people with life-limiting illnesses in Mexico face accessing palliative care, with a special focus on access to pain treatment. It analyzes current policies in the areas of healthcare, health insurance, training of healthcare providers and medicine availability in light of Mexico's international and national legal obligations.

The report urges the Mexican government to fully integrate palliative care into the public healthcare system, ensuring that this health service and essential pain medicines like morphine are accessible to all patients who need them.



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Doña Remedios Ramírez Facio, 73, who has pancreatic cancer, shows a doctor at the palliative care unit of the National Cancer Institute in Mexico how severe her pain was before she was started on morphine.