



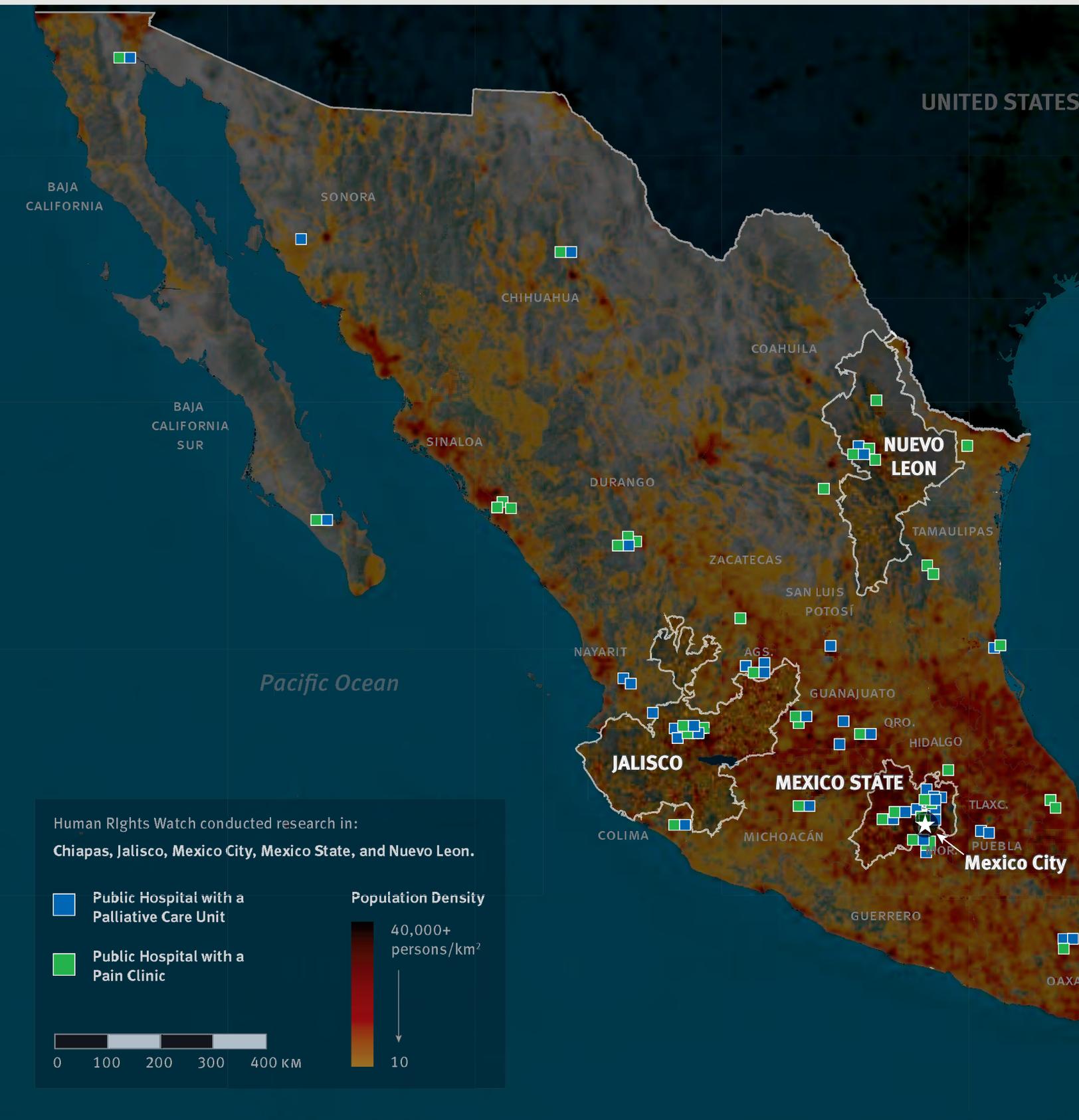
HUMAN  
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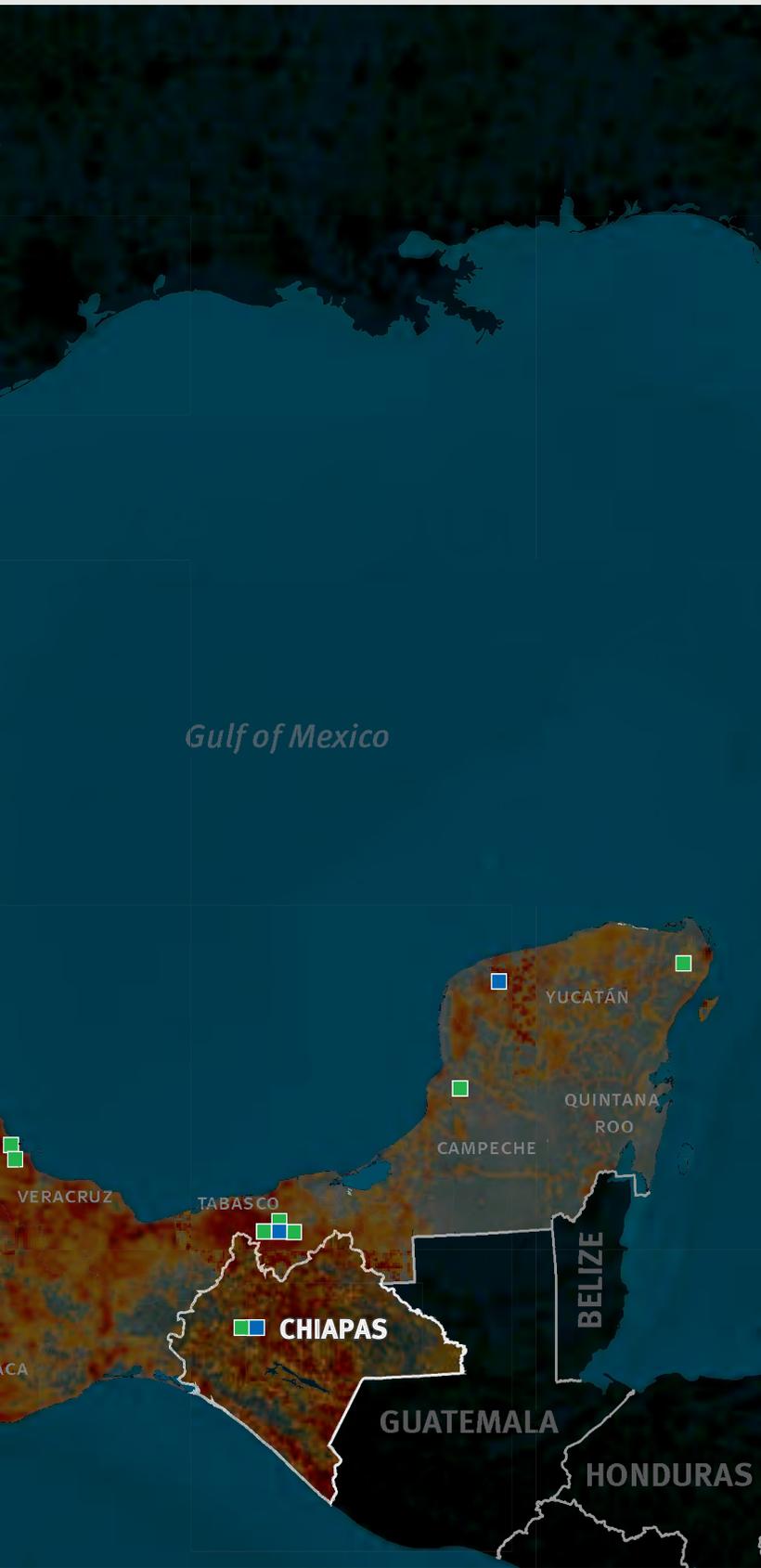
## CARE WHEN THERE IS NO CURE

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.





# 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.<sup>1</sup> 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.<sup>2</sup>

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.<sup>3</sup> 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.<sup>4</sup>

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.<sup>5</sup> A WHO study found that people who live with chronic pain are four times more likely to suffer from depression or anxiety.<sup>6</sup> 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.”<sup>7</sup> 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.<sup>8</sup>

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.<sup>9</sup>

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).<sup>10</sup> 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.”<sup>11</sup> 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.<sup>12</sup>

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.<sup>13</sup>

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.<sup>14</sup> 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.<sup>15</sup>

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.<sup>16</sup>

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.<sup>17</sup> 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.<sup>18</sup>

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.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup> Moreover, a small percentage of Mexicans were covered by private insurance.<sup>22</sup> 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.<sup>23</sup>

The uninsured faced impoverishing out-of-pocket costs, ill-defined benefits, and medicine shortages due to budgetary limitations.<sup>24</sup> 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.”<sup>25</sup>

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.<sup>26</sup> Seguro Popular provides a specific package of personal healthcare interventions and medicines at the primary and secondary levels of care.<sup>27</sup> As of 2014, the package—the Universal Catalogue of Health Services—contains 285 healthcare interventions.<sup>28</sup> 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).<sup>29</sup> As of 2013, Seguro Popular provided health insurance to approximately 55.6 million Mexicans.<sup>30</sup>

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.<sup>31</sup> The fragmentation of Mexico's insurance schemes creates disparate standards and operating norms at health institutions across the country.<sup>32</sup> 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.

<sup>1</sup>WHO, “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.

<sup>2</sup>In 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](http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf) (accessed June 27, 2014), para. 7.

<sup>3</sup>Pain 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.

<sup>4</sup>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](http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_28-en.pdf), para. 7.

<sup>5</sup>Frank 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.

<sup>6</sup>Oye 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.

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

<sup>8</sup>Randall 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.

<sup>9</sup>Julie 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](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.

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

<sup>11</sup>United 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](http://www.incb.org/incb/convention_1961.html) (accessed January 15, 2009).

<sup>12</sup>The 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).

<sup>13</sup>WHO 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](http://www.who.int/medicines/areas/quality_safety/ACMP_BrNote_GenrL_EN_Apr2012.pdf?ua=1) (accessed June 13, 2014).

<sup>14</sup>A 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>.

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

<sup>16</sup>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](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.

<sup>17</sup> For the definition of universal health coverage, see [http://www.who.int/health\\_financing/universal\\_coverage\\_definition/en/](http://www.who.int/health_financing/universal_coverage_definition/en/) (accessed June 3, 2014).

<sup>18</sup> Ibid.

<sup>19</sup> 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](http://www.conapo.gob.mx/es/CONAPO/Aspectos_Generales_de_los_resultados_de_las_Proyecciones_de_Poblacion) (accessed June 27, 2014).

<sup>20</sup> 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](http://www.borderhealth.org/files/res_822.pdf).

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

<sup>22</sup> 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](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.

<sup>23</sup> 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](http://www.who.int/whr/2000/en/whroo_en.pdf?ua=1) (accessed July 18, 2014), p. 153.

<sup>24</sup> 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](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](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2050656), pp. 25, 49-50.

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

<sup>26</sup> 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](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688), pp. 1468-1469.

<sup>27</sup> 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](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688), p. 1470.

<sup>28</sup> 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.

<sup>29</sup> 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](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2048688), p. 1470.

<sup>30</sup> 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](http://www.seguro-popular.gob.mx/images/Contenidos/informes/INFORME_DE_RESULTADOS_SPSS_2013.pdf) (accessed on September 18, 2014).

<sup>31</sup> Ibid., p. 14-15.

<sup>32</sup> 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.<sup>33</sup> 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.<sup>34</sup>

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 Leño 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.



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<sup>33</sup> 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.

<sup>34</sup> Human Rights Watch interview with Adriana Preciado Pérez, February 22, 2012, Guadalajara.

# 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.*