

# Integrated oncology and palliative care: five years experience at the National Cancer Institute of Mexico

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## Abstract

Under the national plan for addressing cancer, prevention and detection play important roles. However, the cost of treatments and late diagnosis represent a significant burden on health services. At the National Cancer Institute, more than half of patients present with tumors in advanced stages, and approximately 10% of patients seen for the first time exhibit terminal-stage malignancies, where there are no feasible cancer treatment options, and the patients are instead admitted to the hospital exclusively for palliative symptomatic management. In 2010, the National Cancer Plan began implementing a model of integrative management of palliative care in oncology that has gradually come to include symptomatic palliative care, involving ambulatory, distant and hospitalized management of patients with cancer, in its final stages and, more recently, in earlier stages.

**Keywords:** Integrated oncology; palliative care; terminal cancer care

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## Resumen

En el marco del plan nacional para abordar el cáncer, la prevención y la detección juegan un papel importante. Sin embargo, el costo de tratamientos y diagnóstico tardío representan una carga significativa en los servicios de salud. En el Instituto Nacional del Cáncer, más de la mitad de los pacientes presentan tumores en etapas avanzadas, y aproximadamente el 10% de los pacientes que acuden a consulta por primera vez presentan malignidades en etapa terminal, donde no hay opciones factibles para de tratamiento del cáncer; en su lugar, los pacientes son admitidos en el hospital exclusivamente para manejo sintomático paliativo. En 2010, el Plan Nacional del Cáncer comenzó a implementar un modelo de gestión integral de los cuidados paliativos en oncología que ha logrado gradualmente incluir cuidados sintomáticos paliativos, incluyendo manejo ambulatorio, distante y hospitalizado de los pacientes con cáncer en fase final y, más recientemente, en las primeras fases.

**Palabras clave:** oncología integrada; cuidados paliativos; cuidado del cáncer terminal

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The incidence of cancer is increasing worldwide, representing the second leading cause of death,<sup>1-3</sup> corresponding to 196.3 million years of life adjusted for disability (QALY); 70% of these cases are in underdeveloped countries.<sup>4</sup> Although there have been significant advances in the prevention, diagnosis and treatment of some cancers,<sup>5-7</sup> according to the World Cancer Report published by the World Health Organization, unless effective strategies are established to promote healthy lifestyles, there will be over 15 million patients with cancer worldwide in 2020.<sup>8</sup>

Mexico, with a population of over 120 million inhabitants,<sup>9</sup> is going through an epidemiological transition, where the ageing of the population is leading to the frequent development of chronic nontransmissible diseases. In 2012, the World Health Organization reported that 148 000 new cases of cancer were diagnosed in Mexico, and 78 700 deaths were attributable to this disease, representing a serious public health issue. Under the National Plan for addressing cancer, prevention and detection play important roles. However, the cost of treatments and late diagnosis represent a significant liability for health services.<sup>10,11</sup> At the INCan, approximately 10% of patients seen for the first time already exhibit terminal-stage malignancies for which there are no feasible cancer treatment options, and these patients are therefore admitted in the hospital exclusively for palliative symptomatic management.<sup>12</sup>

This institutional outlook reflects the situation in Mexico and the surrounding region related to the delayed diagnosis of cancer.<sup>13</sup> According to the Worldwide Palliative Care Alliance (WPCA), six million people with cancer require palliative care worldwide, most of whom are adults aged over 60 years living in countries with middle and low incomes.<sup>14</sup> This number is expected to continue increasing.<sup>15</sup>

Palliative care assistance is a program for improving the quality of life and symptom management of patients, including both adults and children, who have chronic degenerative or neoplastic incurable diseases, and for assisting their families. Such programs essentially aim to offer an integrated and multidisciplinary approach to prevent and provide relief from pain, suffering and other physical, psychosocial and spiritual problems related to the illness.<sup>16</sup>

Palliative care is part of a philosophy that promotes life and regards death as a natural process, without influencing the time of its occurrence; support systems are available for patients to live as actively as possible until death and for families to cope with the patient's illness and their own bereavement. Such care can be administered beginning in the initial stages of the disease, along with other treatments intended to prolong life.

## Palliative care and pain clinics

Pain is the most feared symptom by cancer patients. At diagnosis, between 30 and 50% of patients present with pain, and in advanced stages of the disease, from 70 to 90% of patients may present this symptom.<sup>17,18</sup> Efforts aimed at pain relief have combined multiple medical disciplines in the last 40 years, and various drug therapies and interventional approaches have been developed for pain management.<sup>19</sup>

Mexico has been a pioneer in pain management and has a long history in the construction of a national infrastructure of specialized pain clinics.<sup>20-29</sup> As a natural consequence of the high prevalence of severe pain in patients with advanced cancer, which is incurable in end-stage cases, palliative care has been developed in parallel with these clinics.<sup>30</sup> Anesthesiologists, who have historically been considered to be the medical specialists who are best at managing pain, have led to the development of both disciplines. However, pain is only one component of the complex problems that besets patients with terminal cancer, and other symptoms, such as dyspnea, fatigue, anorexia, nausea, constipation, insomnia, depression, delirium and psychosocial needs, are also very common.<sup>11,31,32</sup>

Over more than two decades, palliative care has been promoted in Mexico through different groups.<sup>22</sup> While there is great heterogeneity among programs that offer these services in the country,<sup>33-35</sup> according to the palliative care development index of the Latin American Palliative Care Association, Mexico exhibits one of the highest levels of development in this field.<sup>36</sup> One of Mexico's strengths in this regard is legislation on the subject of palliative care.<sup>37-40</sup>

## INCAN Initiative: integrative model of palliative care in oncology

At the National Cancer Institute, as in the rest of the country, palliative care began within pain clinics, where major advances in pharmacologic and interventional pain management have been achieved.<sup>27-29,41</sup> In 2010, the authorities of the institution created an independent palliative care service, which, in addition to being incorporated into the efforts of many governmental and non-governmental organizations to implement the National Palliative Care Program under the National Plan Against Cancer, in line with WHO recommendations, has driven key measures to develop palliative care with a focus on public health and to achieve an integrative model of oncological palliative care.<sup>42,43</sup>

In the past five years, the INCan palliative care service has progressively integrated the palliative at-

tion given to the care of cancer patients in several stages. Initially, it joined a multidisciplinary working team (unlike what happens at palliative clinics around the country) of physicians with different specialties, who work in coordination with each other and with oncologists as well as psychologists, nutritionists, social workers, priests and volunteers

**Medical attention**

During the first two years, attention was focused on ambulatory management through outpatient clinics, home visits and telemedicine.<sup>44,45</sup> Referrals to oncologists were delayed, and the median survival was 27 days; the number of visits was 564 in 2010 and 680 in 2011 (figure 1). During this period, the benchmarks for and alternatives to palliative care as well as the differences between this service and pain clinics were established. Additionally, education programs within the hospital, the Diploma in Palliative Care, the subject of palliative care at the undergraduate level and the Onco-palliative Network were implemented.

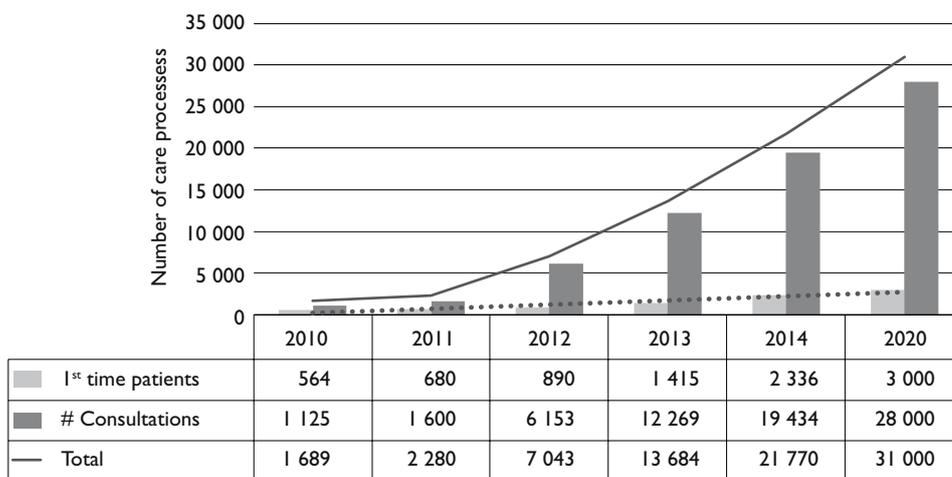
As a result of this strategy, a more consolidated framework was initiated, integrated into the oncology and palliative care services within the hospital, focusing on either complete management or exclusively palliative management. This framework provides management and stabilization of symptoms as well as outpatient monitoring, while for patients at the end of life, their agony is either managed in hospital, or they receive the necessary counseling for home management.<sup>46</sup> Dur-

ing 2014, 927 hospitalized patients were treated, and throughout 2015, an average of 20 daily patients received onco-palliative integrative management. Support for oncologists has included the development an interclinical format that mainly guides younger doctors during their training to understand the benchmarks for palliative care (figure 2). Meanwhile, protocols for access to early palliative care have been initiated, including symptom control, education and family support, along with the possibility of establishing limits for active cancer treatment and living wills.

**Education**

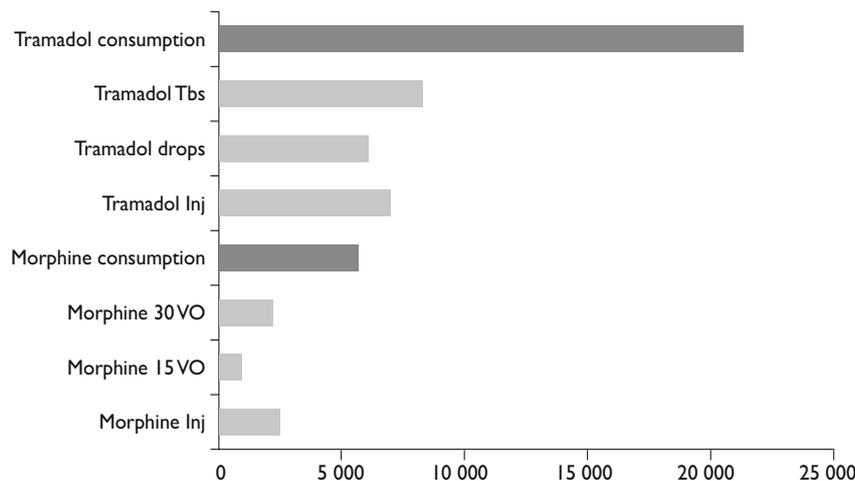
From an educational perspective, the palliative care service offers undergraduate programs, diplomas directed toward the primary care level, highly specialized courses, brief training for different levels of care and training for multidisciplinary teams.<sup>33</sup>

The ethical dilemmas that arise at the end of life are a difficult issue for palliative care teams to address. Therefore, together with the National Bioethics Commission, a classroom workshop was initiated, which could be remotely accessed via *streaming*, led by palliative care residents and palliative care teams from the Onco-palliative Network. The objectives of the workshop were as follows: to promote bioethical attitudes in palliative care; to identify ethical dilemmas in palliative care; to systematically deliberate about conflicts of values that arise during the medical attention given to patients in palliative care; and to solve



Source: Department of Biostatistics and Clinical Archive. INCAN

**FIGURE 1. STATISTICS OF NEW CASES AND PROCESSES OF CARE FOR ONE YEAR OF THE PALLIATIVE CARE UNIT OF INCAN.**



Source: INCAN Hospital Pharmacy Stock, B.S in Chemical Biology, Monrroy, B.S in Chemical Biology, Garcilazo, 2014

**FIGURE 2. OPIOID CONSUMPTION INSIDE THE INCAN, 2014**

any dilemmas that arise through multidisciplinary deliberation and bioethical analysis. The workshop lasted 10 weeks, over 20 hours, and 10 common dilemmas related to the care of patients at the end of life were approached. Opinions about the course were very favorable, and we considered that it should be an important component in the continuing medical education of palliative care teams.

INCan has consolidated the national infrastructure related to palliative care for cancer patients through implementation of the Oncopalliative Network, promoting the strengthening of palliative care teams at State Cancer Centers, Regional High Specialty Hospitals and some General Hospitals dependent on the Ministry of Health, which have joined with oncology services from the hospitals of the Mexican Social Security Institute and the Institute for Social Services and Security for State Workers. Currently, 24 palliative care teams, integrating more than 85 professionals, distributed in 17 states, shape the Onco-palliative Network, and four more states will join during 2016.

### **Palliative care in the clinical practice of oncology**

The palliative care service has worked together with the American Society of Clinical Oncology on short palliative oncology training courses and aims to establish training programs for oncologist palliativists, in which after one year of training in palliative care, oncologists could obtain certification from the Oncology Board. This

strategy would help to implement the integrated view of palliative treatment of cancer patients for which the INCAN palliative care service has searched, as recently proposed by Hui and colleagues.<sup>47</sup>

The integral vision of cancer patient management is consistent with the standards of other countries. Since 2003, the European Society for Medical Oncology (ESMO) has awarded recognition to oncology centers with integrated palliative care, based on 13 care, education and research criteria,<sup>48</sup> in 2015, the INCAN received accreditation as a *Designated Centre for Oncology-Palliative Integration*.<sup>49</sup> This certification is valid for three years and represents the institutional commitment to promote palliative management in patients with advanced cancer, ensuring that fewer patients experience unnecessary suffering.

The palliative care integration model of INCAN oncology represents the first initiative in the country to promote palliative care in the field of standard oncological clinical practice, including management of the disease with symptom management and characteristic personalized attention to palliative care. At present, based on the recommendations of ESMO, which has issued a *Provisional Recommendation* to include early palliative care,<sup>50</sup> this program has been initiated in patients with stage IV non-small cell lung cancer and patients with breast cancer.

Through this initiative, oncologists have acquired skills and management strategies based on the perspective of palliativists, and INCAN palliativists have in turn incorporated the perspective of oncologists into their

daily work. The first result benefits the patient, enriches the dialogue with the family, and makes integral and complete care of the patient possible.

### Handling strong opioids by medical oncologists

One of the indicators for assessing palliative care programs globally is to consider access to opioids.<sup>51</sup> Mexico is one of the countries with the lowest per capita morphine consumption worldwide. Several factors have contributed to poor access to essential medications for pain treatment, a clear example were the previous regulatory complexity of prescribing opioids,<sup>52</sup> which has been a problem for patients outside the hospital setting and for major cities in the country.<sup>53</sup> However, this is not the only reason that strong opioids are not prescribed. At INCan, 70% of visits requiring immediate attention (emergency) are due to uncontrolled pain, but most oncologists within the hospital do not prescribe strong opioids (Allende, manuscript in preparation). During 2014, the INCan pharmacy yielded 5 641 strong opioid doses (morphine); in contrast, the prescription of light opioids (tramadol) exceeded the 21 000 doses. The monthly cost for the patient is close to the equivalent of 30.00 US dollars for morphine consumption, in contrast to the equivalent of more than 200.00 US dollars for tramadol.\* Figure 3 shows the number of pieces supplied at the INCan pharmacy during 2014.

\* Price of 100 tablets of Morphine Sulfate, and the required one-month supply of the usual dosage of Tramadol prescribed (50 mg q8hr). Exchange rate \$16.00 Pesos / \$1.00 US Dollars.

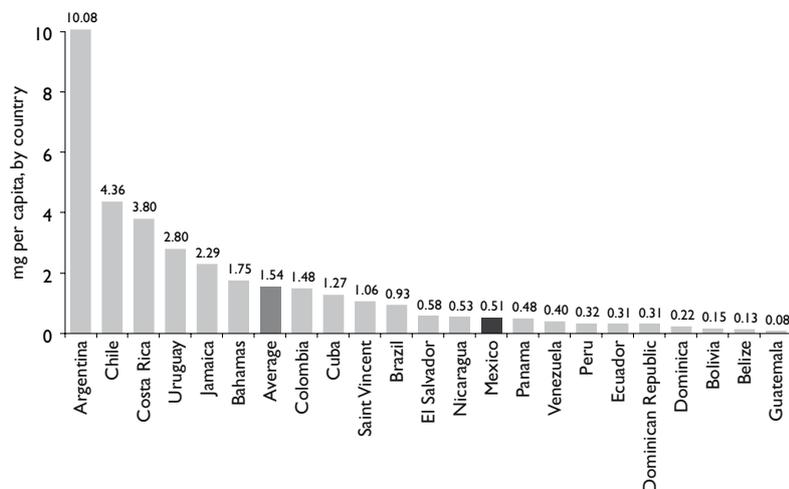
The reasons for non-opioid prescription by oncologists within the institution suggest a shortfall of the prescription protocol because it is assumed that only phycologists, anesthesiologists and palliativists are allowed to prescribe opioids within the INCan (Allende, manuscript in preparation). However, there are also fears among patients, who might contribute to hindering adherence to the treatment. In a survey of 172 patients attending different INCan services, almost half of the patients believed that the prescription of morphine was only for terminal patients (54%), was expensive (65%) and that morphine was an illegal drug (57%).<sup>54</sup>

### The palliative care consolidation at INCan

In this third stage, the palliative care team has attained maturity, but there are still opportunities in the fields of education and assistance. One of the pending issues is development of the research field. Thus far, we have conducted descriptive studies in the medical, nutritional and psychological arenas as well as Phase III trials in lung and breast cancer and international collaborations regarding opioid use for palliative care patients. However, the development of better treatment options for patients aimed at improving the quality of life and death depends on basic and clinical research.

## Discussion

Palliative care has made significant progress in Mexico, though some validation is lacking, as described in recent publications.<sup>13-15,35,36</sup> Mexico currently has legislation related to palliative care,<sup>39-42</sup> and there are therefore



Source: Pain & Policy Group. University of Wisconsin-Madison (2011). WHO Collaborating Center (2011).

**FIGURE 3. MORPHINE CONSUMPTION IN LATIN AMÉRICA, 2011 (MG PER CAPITA, BY COUNTRY)**

significant efforts being made to accelerate the regulatory mechanisms for prescribing opioids, and academic options concerning palliative care have increased at both the undergraduate and graduate levels. The INCan has played an active part in promoting these changes; however, we consider one of the greatest achievements to have occurred within the both institution and in the field of oncology at the national level. The oncology integrative palliative model has allowed palliativists to actively participate in patient management together with oncologists, and gradually, when the patient is about to pass away, to lead their management. Additionally, the oncologist continues to see the patient to avoid the feeling of abandonment due to not receiving disease-modifying treatments. The incorporation of palliative care within the institution has allowed the family to be trained in their role as informal caregivers in a tangible way and even for the patient to decide to die at home, thus avoiding the use of valuable resources destined for the treatment of other patients. However, late referrals remain a problem for the development of an integrative program, as unnecessary treatments at the end of life cause physical, emotional and economic attrition among the family and great suffering to the patient.<sup>11</sup> Intervention by a palliative team in the last 24 hours of life or in the phase of agony in hospitalized patients can reduce the emotional burden on the treating physician but does not allow the transition that is sought through palliative integration.

Education is the basis for achieving changes. Simultaneously with palliative care programs at all levels, rotations have been developed for INCan oncology residents, and other centers with oncology services will replicate this model, incorporating the needs of each particular institution. A pending issue is operationalization of the benchmarks and alternative models at all levels of treatment attention. At present, home visit care is available in some Mexico City delegations, but there is still a need to add the first and second levels of care. End-of-life research faces important challenges in methodological and ethical terms, which will be a focus over the next five years of the development of the service.

*Declaration of conflict of interests.* The authors declare that they have no conflict of interests.

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