

End-of-Life Care in Latin America

abstract

Cancer has become a global pandemic with disproportionately higher mortality rates in low- and middle-income countries, where a large fraction of patients present in advanced stages and in need of end-of-life care. Globally, the number of adults needing end-of-life care is greater than 19 million, and up to 78% of these patients are living in low- and middle- income countries. In the Americas alone, more than one million people are in need of end-of-life care, placing an enormous burden on local health systems, which are often unprepared to meet the challenge presented by this complex patient population. In Latin America, cancer care is characterized by the presence of vast inequalities between and within countries, and the provision of end-of-life care is no exception. Disparities in access to advanced care planning, with a lack of provision of adequate palliative care and pain medication, are common in the region. These shortcomings are related in large part to inadequate or inappropriate legislation, lack of comprehensive national palliative care plans, insufficient infrastructure, lack of opportunities for clinical training, unreliable reporting of data, and cultural barriers. This report reviews the current status of end-of-life care in Latin America, focusing on identifying existing deficiencies and providing a framework for improvement.

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INTRODUCTION

Recently, noncommunicable diseases, such as cancer, have become a global pandemic with disproportionately higher rates in low- and middle-income countries (LMICs).¹ Aging of populations, paired with a concomitant transition from infectious diseases to noncommunicable diseases, has had a tremendous impact on mortality risks, and LMICs have struggled to adapt to this changing epidemiologic landscape.² By 2020, it is estimated that more than 100 million people older than 60 years will be living in Latin America (LA) and the Caribbean and that more than half of this population will live beyond 80 years.³ In LA alone, more than one million new cancers and up to 600,000 cancer deaths occur each year,⁴ placing a considerable burden on local health care systems. This is worsened by a large proportion of patients presenting with advanced disease at diagnosis⁵ and thus requiring greater expenditure and increasingly complex interventions in their care. Globally, the number of adults in need of end-of-life care is greater than 19 million, with 78% of these patients living in LMICs. In the Americas, it has been estimated that 2,588,117 people are in need of end-of-life care, of whom roughly 40% have cancer.⁶ In this context, it has become essential for LA to build and strengthen infrastructure to provide adequate end-of-life care. Unfortunately, in this regard, the region has lagged behind more developed countries, and vast inequalities remain related to access to advanced planning, with a lack of provision

of adequate palliative care and pain medication. These regional shortcomings are related to inadequate legislation, insufficient infrastructure, lack of opportunities for clinical training, unreliable reporting of data, and cultural barriers. This report reviews end-of-life care in LA, focusing on identifying the existing deficiencies and providing a framework for improvement.

LEGISLATION ON END-OF-LIFE CARE IN LATIN AMERICA

Since 1990, WHO has sought to integrate palliative care into existing health systems, including advice and guidelines for governments on priorities and how to embed palliative care into national cancer control programs.⁷ Recently, the World Palliative Care Alliance has recommended that all governments integrate palliative care into health care programs as an effective way to strengthen existing health systems.⁸ WHO⁹ and the World Palliative Care Alliance have joined forces in recommending that countries specifically include in their health systems laws and guidelines that acknowledge and define the role of palliative care within the system, recognize palliative care as a distinct medical subspecialty, and provide appropriate licensure of palliative health care providers, with the goal of defining a national strategy on palliative care.⁶

In LA, end-of-life care in the form of palliative services and educational resources has increased recently, more so in some countries, such as Costa

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Rica, Chile, Argentina, and Uruguay, than in the rest of the region.¹⁰ However, although better integration of palliative policies could benefit millions of patients and their families throughout the region, only four countries (Uruguay, Mexico, Colombia, and Panama) have adopted national palliative laws.^{11,12}

Panama was the first country in the region to launch a national palliative care policy in 2011.¹³ Similar legislation was introduced in Uruguay in 2013.¹² Soon thereafter, in 2014, Mexico and Colombia passed national palliative laws. The official Mexican norm (NOM-011-SSA3-2014) aims to establish specific palliative criteria and adequate delivery of services.¹⁴ Meanwhile, the palliative care law in Colombia aims to regulate the rights of patients and their families with respect to terminal disease, including the management of pain and other physical, emotional, social, and spiritual symptoms.^{14,15}

In LA, it is generally more common to find sections within broader health care laws that regulate palliative and end-of-life care than to find dedicated palliative care laws. Although only four countries have specific palliative care legislation, seven countries have a national palliative care plan (five of which are integrated with plans for cancer or pain), and 13 have a national cancer program that includes palliative care within the program's framework¹¹ (Table 1 and Fig 1A). Two examples of successful, high-quality, and integrated palliative care programs within LA are in Chile and Costa Rica. They rank as the best in LA according to the 2015 Quality of Death Index.²³ This index uses quantitative and qualitative indicators of end-of-life care to evaluate local programs according to the following five criteria: palliative and health care environment, human resources, affordability of care, quality of care, and the level of community engagement.²³

ADVANCED CARE DIRECTIVES IN LA

Advanced directives (ADs) are legal documents that allow patients to express decisions about their end-of-life care when patients have the full capacity to do so; the document defines the patients' wishes about treatments or interventions that may arise in the future when they are incapacitated or unable to make such decisions themselves.²⁴ ADs, in the form of living wills, were first created in the United States in the late 1960s,²⁵ but it was not until the 1991 Patient Self-Determination Act that the completion of ADs was included in federal legislation.²⁶ The US example was followed by other Western nations, and the Council of Europe included ADs as a right in Article 9 of the 1997 Convention of Human Rights and Biomedicine.²⁷

Countries in LA have lagged behind developed nations in the inclusion of ADs into their legal framework, and only a handful of countries have specific federal or regional laws pertaining to ADs. Although all countries include the right to informed consent in their laws (as well as the right to refuse treatments), only six countries (Argentina, Brazil, Colombia, Mexico, Panama, and Uruguay) have specific legislation regarding an AD document and the requirements to create one (Table 2 and Fig 1B). Panama's law was the earliest such law (Ley No. 68 of 2003),¹⁷ which includes a chapter on ADs within a broader legislation regarding patients' rights. However, the first law specifically concerning ADs in LA was published in Mexico City in January 2008 (Ley de Voluntad Anticipada).¹⁸ The original version of this law made it difficult for patients to draft their own document because the presence of a notary public was needed for an AD to be valid; the law was reformed in 2012 to eliminate this requirement.¹⁸ Different versions of this law have since been adopted by various Mexican states,³⁰ and since 2009, the federal Ley General de Salud (General Health Law) includes ADs as a patient's right.²⁸ Other countries in LA that have legislated on ADs are Uruguay (Ley No. 18.473¹⁹) and Argentina (Ley 25.529²⁹ and Ley 26742²⁰) in 2009, Brazil (Resolução CFM No. 1.995/2012²¹) in 2012, and Colombia (Ley Consuelo Devis Saavedra¹⁵) in 2014.

Only the Mexican, Uruguayan, and Brazilian laws are entirely dedicated to ADs, whereas others include ADs within broader documents. Two such documents, those in Brazil²¹ and Colombia,¹⁵ do not include specific instructions on how to draft ADs, and both the Colombian¹⁵ and Mexican¹⁸ laws make ADs available only to people who are deemed terminally ill (defined as an estimated life expectancy of less than 6 months in Mexico¹⁸ and as a "fatal short-term prognosis" in Colombia¹⁵). In Uruguay, Mexico, and Panama, ADs can be signed by the patient in front of a witness at any location, whereas in Argentina, they must be signed in front of a notary public or a judge. The adoption of these laws is difficult to evaluate because of a lack of published results. In Mexico City, only 3,000 ADs were signed between 2008 and 2014,³¹ with 48% of these signed in private hospitals and only 21% signed in public hospitals.³²

EXISTING PALLIATIVE CARE INFRASTRUCTURE IN THE REGION

The beginnings of palliative care services in LA can be traced back to the 1980s, when teams from Colombia and Argentina started implementing

Table 1. Palliative Care Health Policies in Latin American Countries^{11,16}

Country	National Law	National Cancer Program Including Palliative Care	National Primary Care Program Including Palliative Care
Argentina	No	Yes	No
Bolivia	No	Yes	No
Brazil	No	Yes	Yes
Chile	No	Yes	Yes
Colombia	Yes	Yes	No
Costa Rica	No	Yes	Yes
Cuba	No	Yes	Yes
Dominican Republic	No	No	No
Ecuador	No	Yes	No
El Salvador	No	No	No
Guatemala	No	Yes	No
Honduras	No	No	No
Mexico	Yes	Yes	No
Nicaragua	No	Yes	No
Panama	Yes	Yes	Yes
Paraguay	No	Yes	No
Peru	No	Yes	Yes
Uruguay	Yes	Yes	Yes
Venezuela	No	Yes	Yes

inpatient and outpatient services, respectively. Today, all countries in LA have some form of palliative care provision,¹¹ and in the past 5 years, there has been a huge increase in available services.

WHO and the Worldwide Hospice Palliative Care Alliance have classified global development of palliative care services into levels, ranging from level 1 (no known hospice palliative care activity) to level 4b (advanced integration of palliative care into the health system; Fig 1C).²² In LA, there is considerable heterogeneity in the level of development of palliative services. With the exception of Chile (level 4a), Costa Rica (level 4a), and Argentina (level 3b), most countries are considered to be at level 3a or 2³⁶ (Table 3 and Fig 1C). Within each country, palliative care provision is limited to large urban, privileged centers.³³

The LA region has a total of 922 palliative care services (1.63 services per million people), ranging from 0.024 services per million in Honduras to 14.65 per million in Costa Rica. In comparison, Austria, a level 4b country, has 29.4 services per million inhabitants.⁶ Almost half (46%) of the existing services in the region are located in Argentina and Chile, which account for only 10% of the total LA population.^{11,16}

Throughout LA, palliative services are provided either at hospital-level care or in the community. Forty-three percent of the services in the region are located exclusively in hospitals, where multidisciplinary support teams comprised mainly of palliative care physicians and nurses are the most frequent model of palliative care. Approximately one third of services in LA are provided at the community level, with home care teams being the most frequent type of service provided.^{11,16}

The provision of palliative care is often carried out by teams working at hospitals who also work in primary care centers—so-called multilevel services—which account for 20% of all community-level services provided in the region. These mixed services are most frequent in Costa Rica, Uruguay, and Chile.¹¹

Most of the existing palliative services are provided by a multidisciplinary team, consisting of a medical doctor, nurse, and often a psychologist, social worker, or other health care professional. These services are generally located in big cities, and most are tailored to suit the adult population, as few programs exist for pediatric patients.³⁴ Regarding shortages of services throughout the region, six countries in the region have no hospice, eight do not have home care teams, and 13 do not have palliative care service at community centers.^{11,35}

As in other countries in the world, palliative care in LA is commonly linked to cancer care, with approximately a quarter of the services reported to be exclusively for patients with oncologic conditions. This linkage initially helped palliative care to be implemented within an already established network of cancer care provision; however, it limited the provision of services for nononcologic patients.

Proper palliative care infrastructure is one of the key components of the WHO Public Health Model for integrating palliative care into a country's health care system.⁹ Despite important efforts being made in different LA countries to improve access to palliative care, it is far from being accessible and affordable to the majority of the population that could benefit from this care; because palliative care provision is centered at specialized hospitals, the community level often remains uncovered.

PALLIATIVE CARE EDUCATION AND RESEARCH IN LA

Education in palliative care in LA has been focused predominantly on physicians. However, less than 15% of physicians working in palliative care have

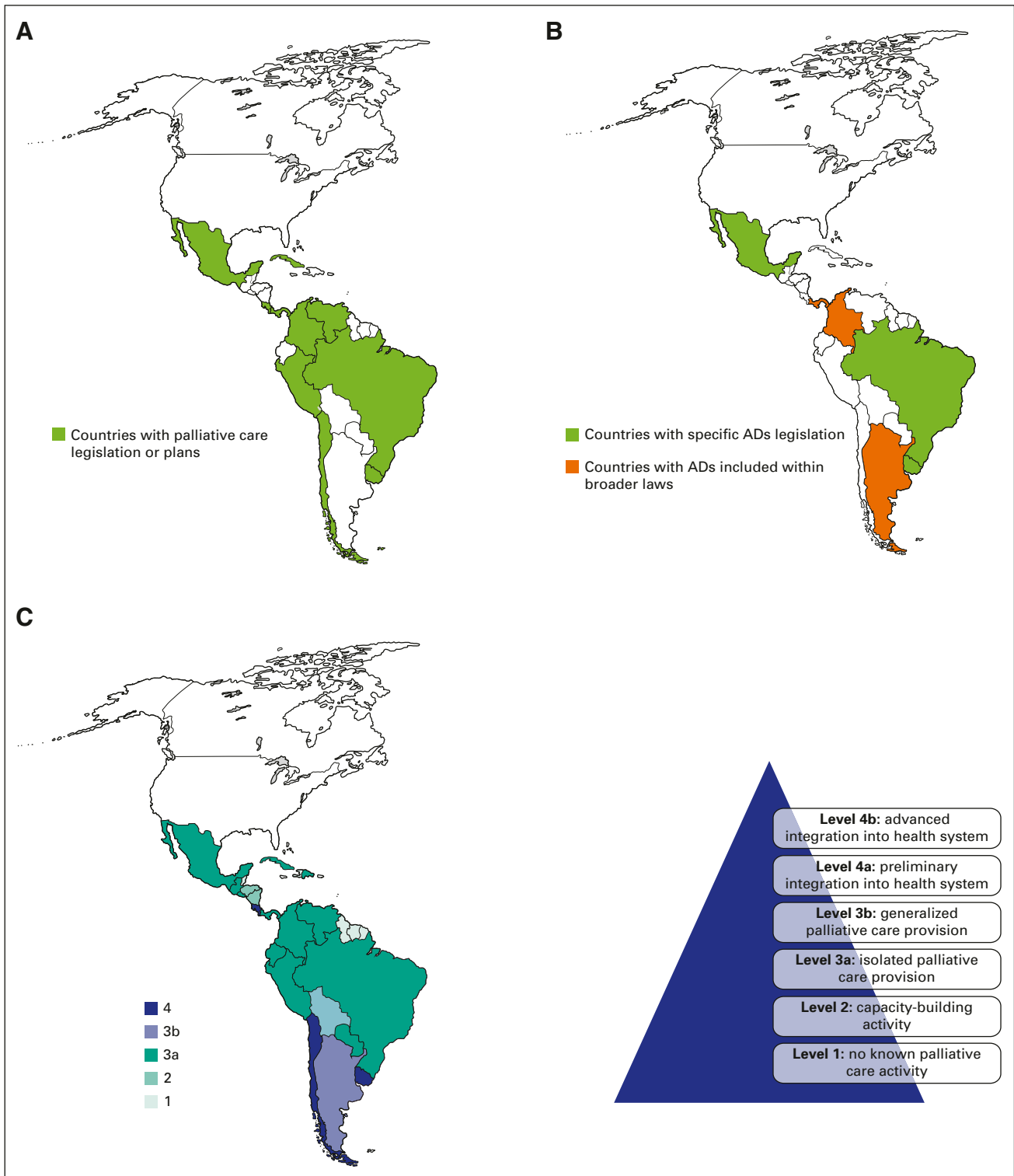


Fig 1. Maps depicting the current status of (A) palliative care legislation and policies, (B) advanced directives (ADs) legislation, and (C) levels of palliative care development in Latin America. Data adapted.^{11,15,16-22}

received palliative-specific education as part of their undergraduate training.³⁶ Only 13.5% of medical schools offer some kind of palliative care studies in an undergraduate program (ranging from just 1 hour of study to a full independent study subject). Furthermore, the number of

palliative teachers is limited. The regional average is 14 teachers per country, and totals range from zero teachers in Bolivia and Honduras to 45 teachers in Mexico. The number of nonmedical teachers is much lower, with a regional average of 1.5 teachers per country.¹¹

Table 2. ADs Legislation in Latin America^{15,17-21,28,29}

Country	Law	Year	Type of Law	AD-Specific Law	Notary Public or Judge Required	Witnesses Required	Only for Terminally Ill Patients
Panama	Ley 68	2003	Federal	No	Optional	Yes (n = 3)	No
Mexico	Ley de Voluntad Anticipada para el Distrito Federal	2008	State	Yes	Optional (since 2012)	Yes (n = 2)	Yes
Mexico	Reglamento de la Ley General de Salud en Materia de Prestación de Servicios de Atención Médica	2013	Federal	No	No	Yes (n = 2)	No
Uruguay	Ley No. 1874. Voluntad Anticipada	2009	Federal	Yes	Optional	Yes (n = 2)	No
Argentina	Ley 25.529 and Ley 26742	2009 2012	Federal	No	Mandatory (since 2012)	Yes (n = 2)	No
Brazil	Resolução CFM No. 1.995/2012	2012	Federal	Yes	Not specified	Not specified	No
Colombia	Ley Consuelo Devis Saavedra	2014	Federal	No	Not specified	Not specified	Yes

Abbreviation: AD, advanced directive.

In a Chilean study, 25% of residents of various specialties reported that they had received some instruction in palliative care during their undergraduate studies, and only 7% of these residents considered the training sufficient.³⁷ In Colombia, a study among undergraduate students of medical and nursing schools reported low levels of comfort regarding their personal knowledge of relevant palliative care subjects.³⁸

Postgraduate courses in palliative care exist in only 10 of 19 LA countries, and these courses are still predominantly available only for physicians.¹¹ In four of these countries, palliative care is accredited as a specialty or subspecialty, and it is issued as a certificate in the remaining six countries. Chile and Paraguay are two countries where palliative care training exists but remains underdeveloped; in Chile, palliative care is recognized but lacks any specific training courses, and Paraguay has a postgraduate course, but it is not accredited. Since 2010, Argentina is the only country with accreditation for palliative care nursing.¹¹ Palliative care nursing care is also an underdeveloped initiative because it is isolated to only a few countries, namely Argentina and Cuba.

Palliative research groups are located in Chile, Argentina, Mexico, Cuba, Colombia, Peru, Panama, Dominican Republic, and Brazil; however, their contribution to palliative care research in the region has been scarce. A total of 106 original research publications have been identified through 2011 in LA and the Caribbean. This accounts for only 2.1% of global palliative care publications. These publications came from only 10 countries in the region, and more than half were from Brazil.³⁹

Identification and qualification of palliative teams are heterogeneous. Although some teams throughout the region have experienced and qualified palliative care specialists, others have merely completed short seminars and/or online training courses.¹¹

ACCESS TO OPIOIDS IN LA

A country's annual consumption of morphine has been historically considered to represent the extent to which opioids are used to treat cancer pain and an indicator to assess improvements in pain management. Despite the fact that there has been an overall increase in the level of reported opioid consumption in the region,⁴⁰ the consumption of opioids in LA in 2013 was 4.9 morphine-equivalent milligrams per capita, far below the world average of 62.27 mg per capita. By way of example, the average morphine-equivalent consumption of opioids in the European Union and the United States is 42 and 143 times higher, respectively (Fig 2).⁴¹ According to the International Narcotics Control Board, most South American countries (ie, Venezuela, Guyana, Peru, Ecuador, Bolivia, Paraguay, and Suriname) have either inadequate or very inadequate levels of opioid analgesic consumption, less than the threshold of 200 defined daily doses.⁴⁰ Of particular importance is the fact that opioid consumption per capita is directly associated with the number of palliative care services per million inhabitants in a country,¹⁰ because even when palliative medicines are available, a well-implemented palliative care service is necessary to deliver adequate care.⁴⁰

Access to opioid therapy requires both availability and affordability.⁴² Limited resources decrease

Table 3. Palliative Care Development in Latin America and the Caribbean^{11,16}

Country	Level of Development ³¹	No. of Services	No. of Services per Million Inhabitants
Argentina	3b	151	3.76
Bolivia	2	6	0.58
Brazil	3a	93	0.48
Chile	4a	277	16.06
Colombia	3a	23	0.50
Costa Rica	4a	63	14.65
Cuba	3a	51	4.54
Dominican Republic	3a	8	0.80
Ecuador	3a	12	0.83
El Salvador	3a	4	0.64
Guatemala	3a	7	0.48
Honduras	2	2	0.24
Mexico	3a	119	1.06
Nicaragua	2	13	2.14
Panama	3a	9	2.64
Paraguay	3a	4	0.61
Peru	3a	12	0.42
Uruguay	4a	23	7.00
Venezuela	3a	45	1.56
Total		922	1.53

the capacity of governments to subsidize drugs and limit the ability of patients to afford them.⁴⁰ In LA, it is common for even basic, inexpensive formulations to be either insufficient or completely unavailable. According to a report from the Opioid Price Watch Project, in 2015, oral morphine tablets were not available in Mexico City, Mexico; Cali, Colombia; Guatemala City, Guatemala; or Rio de Janeiro, Brazil.⁴³

High opioid prices are associated with regulatory expenses, licensing, taxation, import duties, and poor distribution systems, all of which contribute to unaffordability.⁴⁰ These factors may have contributed to the findings of a cross-sectional study of three LA nations, which found that the median price for oral morphine tablets is actually 5.8 times lower in high-income countries than in LMICs.⁴² As a result, the price of 1 month of injectable morphine is several times the minimum wage in Mexico, where coverage of this drug is not included in the public health system, leading to inaccessibility or catastrophic out-of-pocket expense. Conversely, in Costa Rica and Chile, both of which have less fragmented and more comprehensive health systems,⁴⁴ a wider variety of opioids and formulations is available for free to patients.⁴³

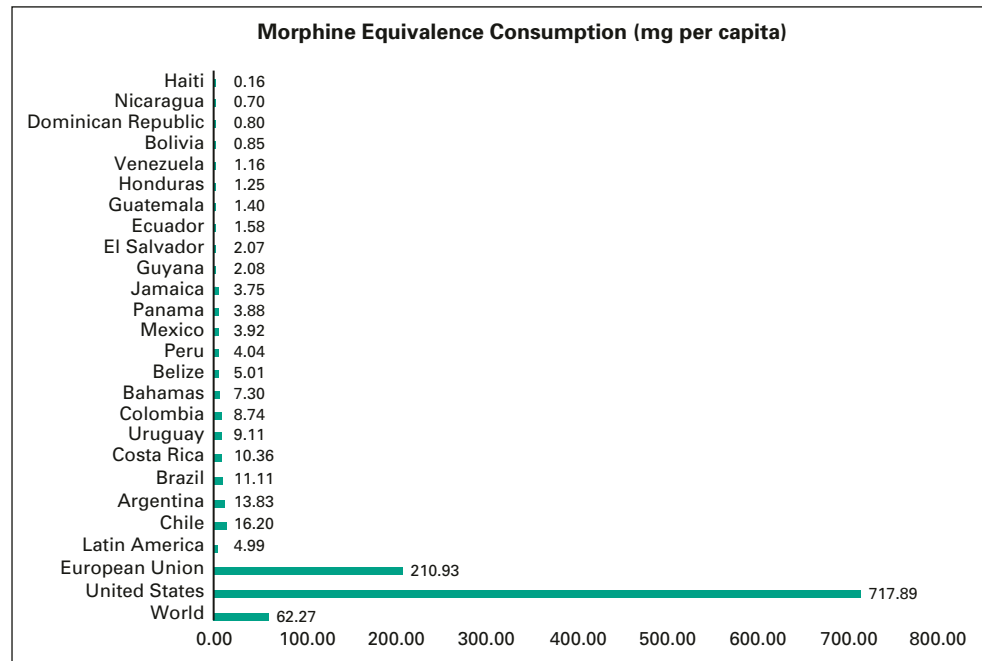
Legal restrictions often limit not only storage and sale of opioids, but also their prescription to patients. For example, some national laws prohibit or restrict opioid use, limiting dosages and concentrations regardless of clinical context or medical need.⁴⁵ Other factors that contribute to the inaccessibility of opioids for patients include unclear and burdensome regulatory requirements,⁴⁰ limited communication and collaboration among those who prescribe and those who regulate opioids,³⁵ lack of training and awareness among medical professionals, fear of opioid addiction, diversion into illicit channels, and restrictive cultural attitudes.⁴⁰

CULTURAL ASPECTS OF END-OF-LIFE CARE IN LA

Delivering high-quality end-of-life care is dependent not only on the availability of appropriate resources, but also on the creation of an environment that successfully integrates the patient and his or her family's cultural values and beliefs into the process.⁴⁶ Unfortunately, qualitative research into the influence of culture on the end-of-life process in LA is scarce, and most of the available information comes from the study of LA immigrants to the United States. Although this research is valuable and provides relevant data, it fails to capture the influence of each nation's specific values on the decision-making process of the patients, their families, and their health care providers.

Latino cultural values regarding end-of-life care have been identified in the literature, and it is recommended that every effort be made to integrate them into palliative care delivery (Table 4). One of the most significant factors is the importance of family participation in decisions involving end-of-life care and advanced care planning. This participation can include the extended family of the patient, and many decisions are ultimately made through family consensus.⁵⁰ Compared with those living in the United States, Latino patients with advanced cancer living in LA are more likely to prefer passive decisional control and share their decisions more often with both their families and their physicians.⁵¹ This may be in part a result of a more paternalistic approach to cancer care by health care providers in LA, because they are less likely to disclose a grave prognosis and more likely to withhold information from the patient at the family's request,⁵² which in turn may lead to late referrals to palliative care services.⁵³ Even though patients in LA may favor a passive or shared decision-making process, the available data show that most of them prefer to receive complete

Fig 2. Consumption of opioids in morphine equivalents, 2013. Data adapted.⁴¹



information about their diagnosis and prognosis.⁵⁴ Spiritual support is also important. For Catholic Mexican-American patients, religiosity and spirituality are essential aspects that lead to a good death. Many believe that God is the only one who has control over birth and death and, hence, death should not be fought against with life-extending measures.⁵⁵

As a result of the relatively recent introduction of legislated palliative care in LA, there is a lack of information regarding attitudes of patients toward planning end-of-life care. Among Latino elders living in California, those with higher levels of cultural assimilation, education, and autonomy were more likely to sign ADs. Most also expressed

preference for a family-centered approach to advanced care planning.⁵⁶ Thus, it seems imperative for LA countries with AD legislation to provide education to health care personnel and to identify barriers to signing of ADs, with a particular emphasis on the inclusion of the patient's family in the process.

In conclusion, cancer incidence will continue to grow in LMICs,^{3,44} which will lead to increased socioeconomic pressure on health care systems. High-quality end-of-life care should be prioritized to improve patient and family quality of life and to reduce and eventually avoid the economic burden of costly inpatient care for advanced disease. In LA, there are notable inequalities between and

Table 4. Latin American Cultural Values Involved in the End-of-Life Care Process⁴⁷⁻⁴⁹

Value	Definition	Importance for End-of-Life Care
<i>Familismo</i>	Emphasis placed on family loyalty, connectedness, and interdependence. Broad support networks including close friends and community leaders.	Discuss family's role up front Engage family members in advance care planning Assess for caregiver burden continuously during the process
<i>Personalismo</i>	Development of warm, personal relationship with the medical professional. The means of professional care are as important as the treatment received.	Foster warm relationships with the patient and relatives Avoid hurrying or imposing decisions
Respect	Dictates differential behavior toward others based on person's authority, age, sex, and socioeconomic status.	Use of formal titles to establish hierarchical relationships Patients and families may consult respected members of their communities as healers or priests
Fatalism	A belief in fate that one's future is preordained or not under one's control.	Identify specific fatalistic beliefs Understand fatalism as a coping strategy
Religiosity and spirituality	Prayer and faith in God are the major sources of comfort and ways to cope with symptoms and dying.	Coping strategy Engage community religious leaders in advanced care planning

within countries regarding the existence of comprehensive legislative frameworks and high-level palliative care infrastructure and training. We believe that tackling these inequalities is the single largest challenge currently facing health care systems in LA. Successfully doing so will allow limited resources to be shifted from costly and prolonged inpatient end-of-life care to more primary and secondary prevention, which in turn could potentially reduce national mortality rates.

To provide high-quality end-of-life care, countries throughout the LA region should design and follow comprehensive palliative care plans and fully integrate end-of-life care into their national health care laws and regulations. Furthermore, patients with cancer in LA should be provided with the option to engage in advanced care planning from the outset of their disease, and ADs should be made legal, easily communicated, and accessible. There is also an urgent need to improve

palliative infrastructure, increase the availability of pain medication, and provide adequate training to all health care providers taking care of patients with cancer. Additionally, it is fundamental for researchers and health care systems to report and publish local data on the provision of end-of-life care to identify and overcome current shortcomings. Qualitative data on the cultural perspectives and social aspects of end-of-life decisions are also urgently needed to design and provide individualized care suitable for each patient's preferences and beliefs. To urgently address the socioeconomic burden of cancer in LA, sustained efforts are needed to improve education, enhance research, expand access to medication, and design a culturally appropriate approach for providing compassionate and appropriate end-of-life care for patients with cancer in the LA region.

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