

Assessing Need for Palliative Care Services for Children in Mexico

Marylou Cardenas-Turanzas, MD, DrPH,^{1,2} Horacio Tovalin-Ahumada, MD, DrPH,³
Carlos Guillermo Romo, MD,⁴ and Regina Okhuysen-Cawley, MD⁵

Abstract

Background: Pediatric palliative care increasingly became integrated into health care institutions worldwide over the last decade. However, in Mexico and other developing countries with large populations of children, little is known regarding the need for palliative care services. We aimed to assess the need for palliative and end-of-life care for children dying in public hospitals affiliated with Secretaria de Salud in Mexico.

Measurement: We conducted a retrospective review of deaths of children (1–17 years old) occurring during 2011 and determined deaths associated with underlying complex chronic conditions by reviewing the four causes of death listed in the death certificate. We collected sociodemographic and clinical data and utilized univariate and multivariate analyses to determine factors associated with complex chronic conditions.

Results: A total of 2715 pediatric deaths were studied. We found 41% were associated with a complex chronic condition. The most frequent types of conditions were malignancies (47%), neuromuscular (18%), cardiovascular (12%), and renal (10%). Children with renal and malignant conditions died at an older age than children with other types of complex chronic conditions. Multivariate analysis indicated the independent predictors of death with complex chronic condition were no indigenous ethnicity, lack of admission to the intensive care unit during the final hospital stay, and having affiliation with an institution for health care.

Conclusions: A large proportion of pediatric deaths are associated with complex chronic conditions indicating the provision of adequate funding for professional education and palliative care initiatives for children in Mexico, should be a topic of the national health care agenda.

Introduction

IN THE LAST DECADE, pediatric palliative care increasingly became integrated into health care in the United States and other countries with development of pediatric palliative care teams providing services at home or in-hospital for children with terminal chronic conditions. In Mexico and other developing countries sharing economic constraints and large populations of children, little is known about the prevalence of chronic conditions in children, as well as their need for palliative care services.¹ Recent reports on the status of palliative care identified only 1.63 units (units mean services, units, or teams) of palliative care per 1 million inhabitants in Latin America² contrasting with 18–20 units per million inhabitants in European countries such as Belgium, Ireland, and Iceland.³

According to the Instituto Nacional de Estadística y Geografía⁴ (equivalent to a National Census Bureau), Mexico has

a population slightly over 112 million and of this 35% are children less than 18 years old. As a first step into planning palliative care programs we aimed to assess the need for palliative care for children dying from complex chronic conditions in hospitals of Secretaria de Salud in Mexico.

Methods

We conducted a retrospective review of discharges from hospitals of Secretaria de Salud (Health Ministry) in Mexico during the year 2011. Secretaria de Salud is one of the government-funded and public national health care systems covering about 24 million Mexicans.⁵ The public-use data file was provided by the Sistema Nacional de Información en Salud (National System for Health Information) a branch of the Secretaria de Salud. The Institutional Review Board of The University of Texas MD Anderson Cancer Center approved the study.

¹Department of Leukemia, The University of Texas MD Anderson Cancer Center, Houston, Texas.

²Sistema Nacional de Investigadores, Consejo Nacional de Ciencia y Tecnología, Mexico City, Mexico.

³Facultad de Estudios Superiores–Zaragoza, Universidad Nacional Autónoma de México, Mexico City, Mexico.

⁴Department of Neurology, University of Arkansas for Medical Science, Little Rock, Arkansas.

⁵Department of Pediatrics, Baylor College of Medicine, Houston Texas.

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We selected patients who died in the hospital, age 1 to 17 years old, and determined deaths associated with complex chronic conditions based in *International Classification of Diseases–10 (ICD-10)* codes as described by Pousset et al.⁶ and Feudtner et al.^{7,8} We classified complex chronic conditions as malignancies, neuromuscular, cardiovascular, respiratory, renal, gastrointestinal, hematologic or immunodeficiency, metabolic, and other congenital or genetic defects. Immunodeficiency cases were excluded because of confidentiality. Each category included several diseases; further details are shown in Table 1. Children were classified as having a complex chronic condition versus not by using four variables of *ICD-10* codes equivalent to the causes of death listed in the death certificate. Our study outcome was the cause of death, categorized as complex chronic condition versus not.

We collected data on age, gender, ethnicity (indigenous versus not indigenous), language spoken (Spanish or dialect), admission to intensive care unit, hospital-acquired infection, and affiliation to a regular source of health care. Regular sources of care included institutions and private coverage;

details of the institutions included are shown as a footnote in Table 2. The location of the hospital discharging the patient (state and municipality), the number of hospital beds per 1000 inhabitants, and the mean family income per municipality of discharging hospital were also collected. The last two variables were obtained from files available at the National System for Health Information and the National Census Bureau. The mean family income per municipality corresponds to the most recent census report published in 2010.⁴

Statistical analysis

We used the Student’s *t* test to compare continuous variables and the χ^2 test or the Fisher’s exact test to compare categorical variables. With logistic regression we determined independent predictors of having complex chronic conditions by entering in a model factors with *p* value ≤ 0.10 from univariate analyses. In multivariate analysis, age was entered *a priori*.

TABLE 1. THE FREQUENCIES OF CATEGORIES AND SUBCATEGORIES OF COMPLEX CHRONIC CONDITIONS AND THE MEAN AGE AT DEATH OF CHILDREN WHO DIED AT HOSPITALS OF SECRETARIA DE SALUD IN MEXICO DURING 2011

<i>Complex chronic condition categories</i> n = 1105 (100%)	<i>Subcategories</i>	<i>Median age at death</i>
Malignancies n = 522 (47%)	Malignant neoplasms including lymphoid, hematopoietic, and related tissue	9 years
Neuromuscular n = 198 (18%)	Brain and spinal cord malformations	8 years
	Mental retardation	
	Central nervous system degeneration and disease	
	Infantile cerebral palsy	
	Epilepsy	
Cardiovascular n = 138 (12%)	Muscular dystrophies and myopathies	3 years
	Heart and great vessel malformations	
	Cardiomyopathies	
	Conduction disorders and dysrhythmias	
Renal n = 109 (10%)	Congenital anomalies	14 years
	Chronic renal failure	
Other congenital or genetic defects n = 62 (6%)	Chromosomal anomalies	2 years
	Bone and joint anomalies	
	Diaphragm and abdominal wall	
	Other congenital anomalies	
Respiratory n = 32 (3%)	Respiratory malformations	4 years
	Chronic respiratory disease	
	Cystic fibrosis	
Gastrointestinal n = 32 (3%)	Congenital anomalies	7 years
	Chronic liver disease and cirrhosis	
	Inflammatory bowel disease	
Hematology and immunodeficiency n = 8 (0.7%)	Sickle cell disease	2 years
	Hereditary anaemia	
	Hereditary immunodeficiency	
	Human immunodeficiency virus disease ^a	
Metabolic n = 4 (0.4%)	Amino acid metabolism	6 years
	Carbohydrate metabolism	
	Lipid metabolism	
	Storage disorders	
	Other metabolic disorders	

Note: Percentages may not add up to 100 due to rounding.

^aCases not included in study, deleted from file by database administrators to protect confidentiality of participants.

TABLE 2. UNIVARIATE ANALYSIS OF DEMOGRAPHIC AND CLINICAL CHARACTERISTICS ASSOCIATED WITH CHRONIC COMPLEX CONDITIONS IN CHILDREN WHO DIED AT HOSPITALS OF SECRETARIA DE SALUD DURING 2011

Variable	All deaths n (%)	Complex chronic condition n (%)	No complex chronic condition n (%)	p value
Total	2715 (100)	1105 (41)	1610 (59)	—
Age at admission, mean (range)	8 (1–17)	8 (1–17)	8 (1–17)	0.19
Gender				0.64
Male	1447 (53)	583 (53)	864 (54)	
Female	1268 (47)	522 (47)	746 (46)	
Indigenous group				0.02
Yes	78 (3)	20 (2)	58 (4)	
No	2297 (85)	903 (82)	1394 (86)	
Unknown ^a	340 (12)	182 (16)	158 (10)	
Admission to ICU	75 (3)	23 (2)	52 (3)	0.07
Hospital-acquired infection	110 (4)	46 (4)	64 (4)	0.84
Health care affiliation ^b				≤0.001
Yes	1242 (46)	560 (51)	682 (42)	
No	968 (36)	322 (29)	646 (40)	
Unknown ^a	505 (19)	223 (20)	282 (17)	
Mean income in Mexi- can pesos per house- hold in municipality of residency, median (range) ^c	8,432.9 (2,76.3–26,479.4)	8,527.8 (5,66.3– 26,479.4)	8,397.2 (2,76.3–26,479.4)	0.03
Hospital beds per 1000 inhabitants in munic- ipality of residency, mean (range)	0.36 (0–9.9)	0.36 (0–3.0)	0.36 (0–9.9)	0.89

Note: Percentages may not add up to 100 due to rounding.

^aExcluded from analysis presented in table.

^bInstitutions included: Instituto Mexicano del Seguro Social, Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado, Petroleos Mexicanos, Secretaria de la Defensa Nacional, Secretaria de Marina, Servicios de Salud del Gobierno del Estado, Seguro Popular, IMSS Oportunidades and Private Insurance.

^cBased on data from Instituto Nacional de Estadística y Geografía (equivalent to a National Census Bureau), Censo de Población y Vivienda 2010.

ICU, intensive care unit.

We evaluated if using only the underlying cause of death instead of the four variables of causes of death was appropriate to capture cases with complex chronic conditions by calculating areas under the curve of receiver operating characteristics (AUROC) curves for each type of complex chronic condition. Values over 0.70 were considered acceptable.⁹ We determined the number of children in need of palliative care by using the formula provided by World Health Organization¹⁰: number of children in need of palliative care = number of deaths related to complex chronic conditions observed * 0.80. The formula used to determine the number of caregivers (parents, family members, guardians) in need of education was: palliative care education = number of children in need of palliative care * 2. All statistical analyses were conducted using IBM-SPSS Statistics version 19 (SPSS Inc., Chicago, IL). For all analyses, significance was set at $p < 0.05$ (two-tailed).

Results

During 2011, a total of 56,891 patients died in hospitals of Secretaria de Salud, of which 13,576 (24%) were children. Of

these, 2715 (20%) were between 1 and 17 years old. A total of 1105 children (41%) had diagnoses of complex chronic conditions.

The most frequent types of complex chronic conditions were malignancies (47%) followed by neuromuscular (18%), cardiovascular (12%), and renal (10%). These four accounted for 87% of the conditions diagnosed. The proportions of deaths by type of complex chronic condition are shown in Table 1. When evaluating the age at death by type of condition, we found the median age at death secondary to any condition was 8 years (range, 1–17). We observed differences in the age at death by the type of complex chronic condition diagnosed. Compared to children dying with other types of complex chronic conditions, children with renal or malignant conditions significantly died at older age (median = 14 versus 7 years and median = 9 versus 6 years, respectively). The opposite and also significant association was observed for children who died of cardiovascular and other congenital or genetic defects (median = 3 versus 8 years and median 4 versus 8 years, respectively).

Table 2 shows the demographic and clinical characteristics of the patients in the study by diagnosis of complex chronic

conditions. Logistic regression analysis indicated that when compared to children who died without complex chronic conditions, children with these conditions were not likely of indigenous ethnicity (odds ratio [OR]=2.03, 95% confidence interval [CI]=1.13–3.62), were not admitted into the intensive care unit during the hospital stay (OR=1.99, 95% CI=1.12–3.55), and had affiliation with an institution/organization for health care (OR=1.84, 95% CI=1.51–2.25). A total of 127 deaths (11%) were diagnosed with more than one complex chronic condition. These patients were significantly younger than patients diagnosed with one condition, mean age 7 versus 8 years ($p \leq 0.003$). Having an affiliation to health care was associated with having more than one complex chronic condition ($p \leq 0.001$) but it was not associated with gender, ethnicity, admission to the intensive care unit, or intrahospital infection.

When we used only the underlying cause of death and applied the algorithm to capture the cases dying of complex chronic conditions, only 840 (31%) cases were found. By using this approach, the proportion of complex chronic conditions was only 76% of the cases captured when using our initial algorithm that included the four variables of the cause of death. When we determined the AUROC curves comparing the underlying cause of death with the complete algorithm (gold standard) we observed acceptable AUCs only for malignancies (AUC=0.88, 95% CI=0.87–0.90) and cardiovascular conditions (AUC=0.73, 95% CI=0.70–0.77). Other categories of complex chronic conditions obtained inferior AUCs.

Assuming that 80% of deaths of children diagnosed with complex chronic conditions who died would have benefited from palliative care, a total of 884 cases should have received this type of care. The number of parents, caregivers, and guardians in need of education about this type of care was estimated to be 1768.

Discussion

We found that 41% of deaths of children aged 1 to 17 years that occurred in hospitals affiliated with Secretaria de Salud of Mexico were associated with complex chronic conditions. The most frequent types were malignancies (47%), neuromuscular (18%), cardiovascular (12%), and renal (10%). We found children who died of renal and malignant complex chronic conditions tended to be older than children who died of other causes while the opposite was observed for children dying of cardiovascular and other congenital or genetic defects, indicating physicians and nurses caring for these children need to develop appropriate skills to treat, care and communicate with them. These skills may include explaining medical information according to child developmental needs and assessing distressing symptoms not adequately relieved by standard medical interventions.

In multivariate analysis we observed children not belonging to minority ethnic groups were more likely diagnosed with complex chronic conditions. However, this finding may just reflect the low number of children (3%) of indigenous ethnicity included in this study, as well as the low penetration of health care into rural areas where children of Mexican-Indian ethnicities are likely residents.

Our observation of 31% deaths attributed to complex chronic conditions when utilizing the underlying cause of

death is consistent with a report from European countries. In a study conducted by Pousset et al.,⁶ the proportions of complex chronic conditions in five European countries ranged between 27.7% and 35%. We also observed that algorithms using the underlying cause of death underestimate the need for palliative care services excluding approximately 24% of children who may have been diagnosed with complex chronic conditions and in need of this option of care. This observation may be accounted for by health planners when estimating the need for services based in the underlying cause of death.

Pediatric palliative care programs aim to enhance life, reduce suffering, optimize functioning, and provide opportunities for personal and spiritual growth. Although several models of care delivery have been proposed, the choice should be based in needs assessment and available resources of each institution with strong consideration to issues such as the location of the care team (inpatient, outpatient, home, and hospice) and referrals among geographic regions.¹¹

Factors associated with complex chronic conditions explored in this study were limited to those available in the data file and our estimation of need for palliative care does not account for children currently living with complex chronic conditions, indicating the need for these services in Mexico is definitively larger than estimated by our study. We also have to consider that the retrospective design of the study and its institutional level perspective make it impossible to verify the reliability of the data. However, the use of data at the population level provides with an initial view of the types of patients needing the services.

Given the lack of pediatric palliative care programs in Mexico, very few children currently have access to this type of care. To improve access to palliative care, changes at the institutional and health care system level are needed. At the institutional level, palliative care must be offered along with curative treatments. At the system level, implementation of educational programs, improved access to medications and adequate funding to sustain these programs must be warranted.

Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Marylou Cardenas-Turanzas, MD, DrPH
The University of Texas MD Anderson Cancer Center
1515 Holcombe Boulevard, Unit 428
Houston, TX 77030

E-mail: mcardena@mdanderson.org