

## Palliative care needs in Costa Rica by province

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Traducción de artículo original: Picado-Ovares JE, Solórzano-Morera F. Necesidades de atención en cuidado paliativo de Costa Rica según provincia. Acta méd. costarric. 2021;63:113-121 DOI: 10.51481/amc.v63i2.1112

### Abstract

**Aim.** There is a lack of knowledge regarding palliative care needs in Costa Rica, which creates difficulties in being able to distribute resources properly. This study seeks to identify palliative care needs by the province to serve as input for adequate planning and utilization of resources.

**Methods.** The methodology designed by The Lancet Commission on Palliative Care and Pain Relief based on severe health-related suffering was used for 20 diseases with the greatest probable need for palliative care using the database of the Costa Rican Institute of Statistics and Census and databases of the Ministry of Health and the Caja Costarricense del Seguro Social.

**Results.** In Costa Rica, 19502 people required palliative care in 2018, with neoplastic diseases occupying the first place, followed by cerebrovascular diseases, external causes, and HIV-AIDS. Most of the cases are in the central provinces of the country (San José, Alajuela, and Heredia) and the minority in Guanacaste.

**Conclusion.** It was possible to estimate the palliative care needs in Costa Rica by diagnosis and province of residence, documenting that the majority of needs are for non-oncological terminal diseases in the provinces of San José, Alajuela, and Heredia.

**Keywords:** Needs, Care, Palliative Care

**Received Date:** February 09, 2021

**Approved Date:** August 18, 2021

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**Abbreviations:**

**CCSS:** Caja Costarricense del Seguro Social

**ICD 10:** International Statistical Classification of Diseases and Related Health Problems 10.

**INEC:** Instituto Nacional de Estadísticas y Censos / National Institute of Statistics and Census.

**WHO:** World Health Organization  
**HIV:** Human Immunodeficiency Virus-AIDS

**Sources of support.** None

**Conflicts of interest.** No conflicts of interest are considered to exist with the publication of the article.  
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**“Palliative care” refers to the approach aimed at people with advanced diseases and their families when the medical expectation is no longer a cure. It is an approach whose main objective is to improve the quality of life of the patient and his or her family by providing comprehensive care delivered by interdisciplinary work teams.**<sup>1,2</sup>

Each country has particularities in palliative care, so it has been documented as an essential task to calculate the palliative care needs for each region and different methods have been proposed to measure them, usually using causes of death as a starting point.<sup>1, 3-10</sup>

Costa Rica lacks the necessary information to determine palliative care needs that will allow prioritizing the distribution of resources, with distributive justice and optimizing institutional support to the maximum. Currently, resource planning is based on general population projections or local experience.



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This document seeks to estimate the palliative care needs of the Costa Rican population and to analyze their frequency at the national level, according to diagnoses and province of domicile, to provide inputs for planning the distribution and allocation of resources for end-of-life care services.

with severe health-related suffering and defined as “suffering associated with the need for palliative care.”<sup>9</sup>

Initially, a group of experts identified the 20 diseases that generated the greatest need for palliative care in the world. For the classification of these diseases and subsequent calculations, the tenth International Classification of Diseases (ICD-10) codes of these 20 diseases were used (Table 1).<sup>11</sup>

## Methodology

In 2018, the Lancet Commission on Palliative Care and Pain Relief described a new way to measure palliative care needs, starting

**Table 1. Disease codes are chosen by the Lancet Commission according to ICD-10 and the respective multiplier for the deceased and survivors\***

ID	ICD-10 code	Name	Deceased Multiplier	Survivors Multiplier
1	A96,98,99	Hemorrhagic fevers	0.5	1
2	A15-19	Multidrug-resistant tuberculosis	1	0.9
2b	A15-20	Tuberculosis	0.9	0
3	B20-24	HIV/AIDS	1	0.5
4	C00-97	Malignant neoplasms	0.9	Ver cuadro 3
5	C91-95	Leukemia	0.9	0
6	F00-04	Dementia	0.8	0.1
7	G00-09	Inflammatory diseases of the central nervous system (measles, tetanus, rabies, encephalitis, and meningitis).	0.3	0
8 <sup>a</sup>	G20	Parkinson's disease	0.65	0.1
8b	G21-23; G30-32; G36-37; G80-83	other neurological diseases	0.65	0
8c	G35	Multiple sclerosis	1	0.02
8d	G40-41	Episodic disorders (epilepsy)	0.5	0
9	I60-69	Cerebrovascular diseases	0.65	0.15
10 <sup>a</sup>	I05-09	Rheumatic heart disease	0.65	0
10b	I10-15	Hypertensive diseases	0.7	0
10c	I42	Cardiomyopathy	0.4	0
10d	I50	heart failure	0.4	0
11	I25	Ischemic heart disease	0.05	0
12 <sup>a</sup>	J44	Chronic obstructive pulmonary disease (COPD)	0.8	0
12b	J40-43; J47; J60-70; J80-84; J95-J99	Other respiratory diseases	0.5	0
13 <sup>a</sup>	K70-73; K75-K77	Other liver diseases	0.3	0
13b	K74	Cirrhosis	0.95	0
14	N17-19	Renal failure	0.45	0
15 <sup>a</sup>	P07	Low birth weight and prematurity.	0.75	0
15b	P10-P15	Birth trauma.	0.4	0
16	Q00-99	Congenital malformations, deformities, and anomalies	0.6	1
17	S00-99; T00-T98; V01-Y98	External causes: Trauma, poisoning, and some other consequences of external causes.	0.3	2
18	I70	Atherosclerosis	0.35	0
19	M00-97	Diseases of the musculoskeletal and connective tissue system	0.7	2
20	E40-46	Malnutrition	1	0

\*Adapted from Lancet Commission on Palliative Care and Pain Relief. Lancet Commission on global access to palliative care and pain. technical note and data appendix report; 2017 (11).

Estimates were worked on two different groups of this population, **the deceased** (patients who died in the year of study due to one of the 20 diseases) and the **survivors** (patients who suffered from the disease in the year studied). For the final calculation of palliative care needs

for each group of diseases, the Lancet group, based on expert criteria, developed a multiplier for each disease to establish the proportion of deceased persons who were suffering and who would eventually require palliative care. This information is summarized in Table 2.

Table 2. Particular characteristics of some diseases for the calculation of palliative care needs	
Disease	Description
Hemorrhagic fever	In Costa Rica in 2018, no deaths or survivors from this disease were reported.
Tuberculosis	It is divided into multidrug-resistant tuberculosis (resistant to isoniazid and rifampicin treatment) and usual TB. 100% of those who die of multidrug-resistant TB and 90% of those who die of usual TB require palliative care. In Costa Rica, 13% of the deceased belong to multidrug-resistant TB and 87% to the usual TB (Statistics of the Ministry of Health of Costa Rica).
Inflammatory diseases of the central nervous system	They include diseases such as measles, tetanus, trypanosomiasis, rabies, encephalitis, and meningitis. In Costa Rica, there have only been deaths from encephalitis and meningitis.
Neoplastic (survivors)	We have the 2018 data to calculate the palliative care needs needs of the deceased, but the 2018 data needed to calculate survivors is not available, therefore it was replaced with the 2015 incidence and thus to be able to make the survivor estimates.
Dementia, degenerative diseases of the central nervous system, and cerebrovascular diseases (survivors)	To obtain information on the prevalence of these diseases, direct consultations were made with the Health Statistics Area of the CCSS for 2018. The Digital Health Record (EDUS) database was used.

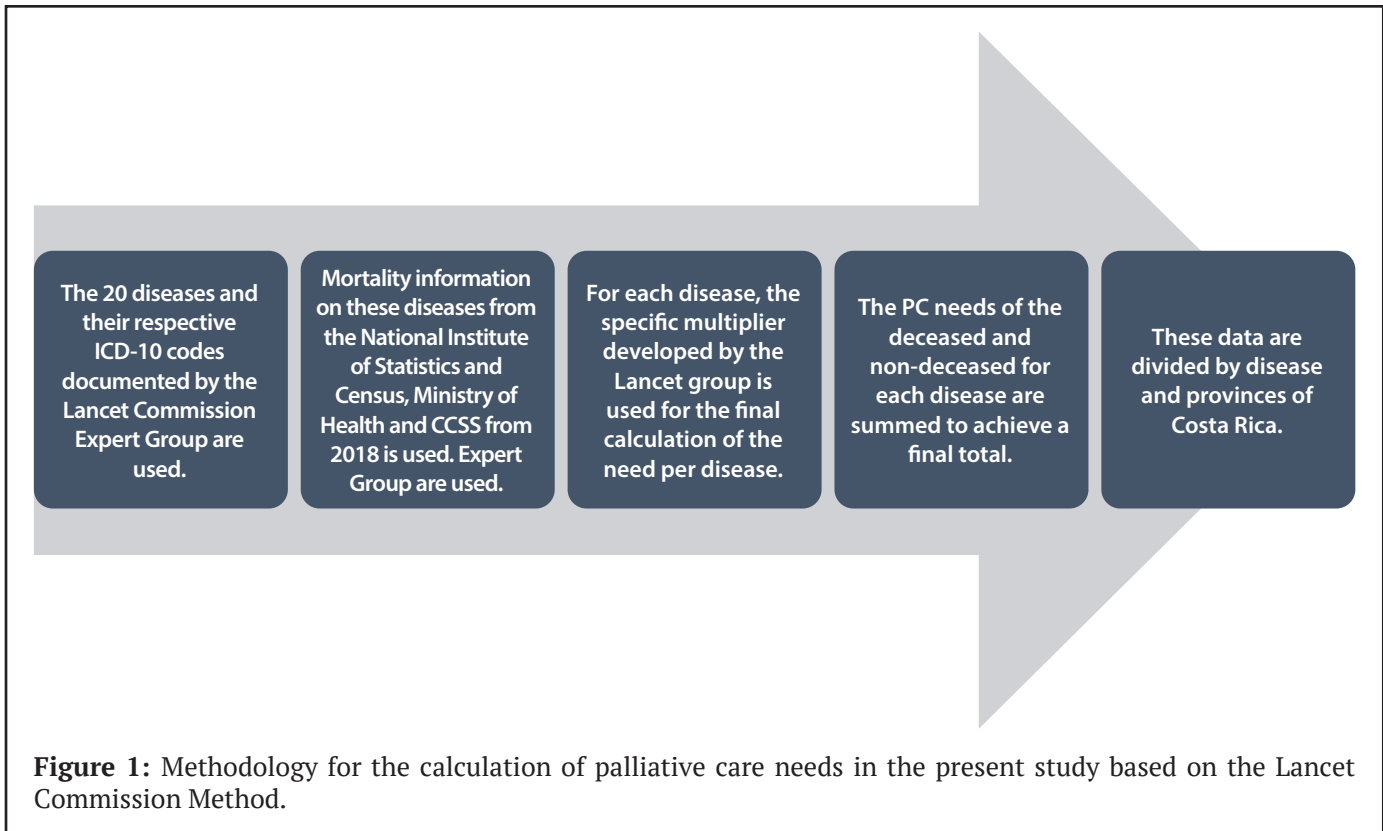
Palliative care needs for each specific disease are calculated from the sum of the product of the deceased for each specific disease in the study year by the

disease-specific multiplier and the patient survivors for each disease with its respective multiplier in the study year; as shown in the formula below:

$$\text{Palliative care needs by specific disease} = \text{deceased by disease in the year of study}^* \text{ specific multiplier} + \text{survivors by disease in the year of study}^* \text{ pecific multiplier}$$

The total need for palliative care would be the sum of the palliative care needs for each specific disease. For the present study, the aforementioned

methodology was used and which is detailed in another publication.<sup>11</sup> The methodology used in this study is summarized in Figure 1:



**a. Calculation of palliative care needs of patients in Costa Rica:**

In the case of the palliative care needs of the group of the deceased, the researchers of this work used the data available from the National Institute of Statistics and Census (INEC), on general deaths in Costa Rica, for the period 2018, as this was the latest period recorded at the time of the study. INEC classifies the causes of deaths using the ICD 10 Codes and allows their analysis by the province of residence. For some particular diseases, the information required for the calculation of need was obtained from data from the Ministry of Health, the Expediente Digital en Salud (EDUS), and the CCSS statistics office, as summarized in Table 2.

As in The Lancet Commission Report, the calculation of palliative care needs by survivors, i.e. those who did not die from one of the conditions in the study year, is also included using the multipliers summarized in the table below.

These individuals may have suffered and therefore need palliative care or pain control as they may have conditions that may have been cured but suffering persists, conditions in which patients

survive for a year or more with a disability, or have pain for years.<sup>11</sup>

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**Results**

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**a. National level palliative care needs.**

Table 3 summarizes the general calculations obtained. Using the methodology described above, it was determined that 19502 people require palliative care in Costa Rica.

At the national level, it was documented that neoplastic diseases occupy first place in the prevalence of conditions requiring palliative care, followed by cerebrovascular diseases, external causes (which include trauma, poisoning, trauma from heat, cold, electricity, and traffic accidents, among others) and HIV-AIDS, and in a distant fifth place, dementia syndromes. When dividing terminal illnesses into oncological and non-oncological, the latter represents 62% of the palliative care needs in the country. This ratio is maintained throughout all provinces, except in Cartago, Limón, and Guanacaste, where the percentage of non-oncological disease is slightly higher.

Table 3. Palliative care needs by disease in 2018 in Costa Rica						
Diseases	ICD-10 codes	Deceased	Survivors	Totals	Percentage	
1 Malignant neoplasms (excluding Leukemia)	C00-C97	4600	2480	7080	36,3%	
2 Cerebrovascular Diseases	I60-I69	930	1592	2522	12,9%	
3 External causes	S00-S99, T00-T98, V01-Y98	829.8	1659.6	2489	12,8%	
4 HIV	B20-B24	185	2295	2480	12,7%	
5 Dementia	F00-F04	262	764	1026	5,3%	
6 Pneumopathies (COPD and other respiratory diseases)	J40-J47, J60-J70, J80-J84, J95-J99	871	-	871	4,5%	
7 Non-ischemic cardiac (rheumatic, hypertensive, cardiomyopathy, heart failure)	I05-I09, I10-I15, I42, I50	762	-	762	3,9%	
8 Disease of the Parkinson's, Multiple Sclerosis, Epilepsy, and other CNS diseases	G20-G25, G30-G32, G40-G41, G80-G83	321	332	653	3,3%	
9 Cirrhosis and other liver diseases	K70-K77	359	-	359	1,8%	
10 Diseases of the musculoskeletal and connective tissue system	M00-M97	111	223	334	1,7%	
11 Congenital malformations, deformities, and anomalies	Q00-Q99	152.4	152.4	305	1,6%	
12 Renal failure	N17-N19	247	-	247	1,3%	
13 Leukemia	C91-C95	203	-	203	1,0%	
14 Low birth weight and prematurity. Birth trauma	P07, P10-P15	55	-	55	0,3%	
15 Ischemic heart disease	I25	48	-	48	0,2%	
16 Tuberculosis and multiresistant tuberculosis	A15-A19	34	0	34	0,2%	
17 Malnutrition	E40-E46	16	-	16	0,1%	
18 Inflammatory central nervous system (meningitis)	G00-09	13	-	13	0,1%	
19 Atherosclerosis	I70	5	-	5	0,0%	
20 Hemorrhagic fevers	A96,98,99	0	0	0	0,0%	
<b>Total</b>				<b>19502</b>	<b>100,0%</b>	

A comparison of palliative care needs by province (see Table 4) shows that most cases are located in the central provinces of the country,

mainly San José and Alajuela. In third place is the province of Heredia. The coastal provinces, mainly Guanacaste, have fewer palliative care cases.

Table 4. Palliative care needs by disease in 2018 in Costa Rica, by province									
Lancet Diseases	San José	Alajuela	Cartago	Heredia	Puntarenas	Limón	Guanacaste	Unknown	Total
1 Malignant neoplasms (excluding Leukemia)	2755	1422	788	716	569	436	412	40	7138
2 Cerebrovascular Diseases	843	518	277	249	198	163	201	72	2522
3 External causes	729	460	228	213	309	311	239	0	2489
4 HIV	1022	315	195	355	77	174	131	212	2480
5 Dementia	387	205	112	113	64	52	54	40	1026
6 Pneumopathies (COPD and other respiratory diseases)	325	135	102	83	85	74	69	0	871
7 Non-ischemic cardiac (rheumatic, hypertensive, cardiomyopathy, heart failure)	233	158	80	63	69	71	89	0	762
8 Parkinson's disease, multiple sclerosis, epilepsy, and other CNS diseases	209	142	70	61	61	46	49	14	653
9 Cirrhosis and other liver diseases	113	70	45	37	35	26	33	0	359
10 Diseases of the musculoskeletal and connective tissue system	139	57	32	34	25	25	23	0	334
11 Congenital malformations, deformities, and anomalies	88	60	28	26	46	35	23	0	305
12 Renal failure	63	38	25	23	18	25	55	0	247
13 Leukemia	74	42	19	23	15	17	13	0	203
14 Low birth weight and prematurity. Birth trauma	15	15	5	2	8	7	3	0	55
15 Ischemic heart disease	16	9	5	5	5	4	5	0	48
16 Tuberculosis and multiresistant tuberculosis	9	9	4	0	5	5	4	0	34
17 Malnutrition	4	2	2	1	4	2	1	0	16
18 Inflammatory central nervous system (meningitis)	5	2	1	1	1	2	1	0	13
19 Atherosclerosis	1	0	0	1	0	0	1	0	5
20 Hemorrhagic fevers	0	0	0	0	0	0	0	0	0
<b>TOTAL</b>	<b>7031</b>	<b>3659</b>	<b>2016</b>	<b>2006</b>	<b>1592</b>	<b>1473</b>	<b>1404</b>	<b>378</b>	<b>19560</b>

When analyzing the 5 diagnoses that justify palliative care needs in the country (see Table 3), 4 diagnoses consistently appear among the causes of palliative care needs in all the provinces of the country. Neoplastic diseases are the first diagnosis that justifies these needs in all of them. The other 3 diseases are HIV-AIDS, cerebrovascular disease, and external causes. Dementias are in fifth place in the provinces of the central valley, pneumopathies in the provinces of Puntarenas and Limón, and heart disease in Guanacaste.

## Discussion

Palliative care needs in the country are proportionally related to the population density of each province, with the provinces with the largest

populations having the greatest need. Cancer is the most frequent disease in all provinces, a phenomenon that occurs worldwide, due to the increase in the incidence of this pathology. When classifying the diseases requiring palliative care into oncologic and non-oncologic, most of the palliative care needs in Costa Rica come from non-oncologic diseases, and the ratio is maintained in most of the provinces, in percentages very similar to those compared worldwide.<sup>1</sup>

Palliative care needs were calculated using two different types of populations, the deceased and the non-deceased (9). However, the deceased group is the largest contributor to the caseload in contrast to previous studies.<sup>1, 9, 10</sup> This is probably due to the adequate national registry of the deceased in the country kept by INEC, which is not the case in other



countries in the world with weaker health systems.<sup>9</sup> In Costa Rica, it is evident that the relationship between non-oncologic and oncologic pathologies is similar to previous studies,<sup>9,10</sup> except for the latest research conducted by the WHO.<sup>1</sup> In this research, the global cases of oncologic disease are much lower, due to the high need for palliative care for non-oncologic causes in all regions, except for the European and American regions. The behavior of Costa Rica is very similar to that presented in the subregion of the American region, as expected.<sup>1</sup>

When analyzing the results specifically by diseases, the increase in the need for palliative care due to external causes is noteworthy, which is double that presented in previous publications,<sup>9</sup> even when compared with the subregion of the Americas,<sup>1,13</sup> where accidents of this type are higher than in other regions of the world.<sup>12</sup> The behavior of this cause is comparable to that of the Eastern Mediterranean and Southeast Asian subregions. Costa Rican culture has aspects of gender and citizen compliance with the law that may explain this behavior.<sup>13</sup>

This study documents that palliative care needs for the cerebrovascular disease are much higher than in the rest of the American region.<sup>1</sup> An increasing trend in cerebrovascular disease mortality in Costa Rica in the last decade can be partially explained by the sustained increase in the burden of risk factors such as age, arterial hypertension, and high body mass indexes.<sup>14</sup>

Concerning HIV, the behavior is similar to that found in the Southeastern subregion and the Americas. In Costa Rica, despite the efforts made, there is evidence of an increasing trend of HIV for multiple sociocultural and health reasons, mainly in San José and Heredia.<sup>15</sup>

On the other hand, palliative care needs for tuberculosis are much lower than those presented worldwide, as well as for hepatopathies.<sup>9</sup> With tuberculosis, the adequate control of the disease by the country's health authorities explains the low number of cases related to this pathology.<sup>16</sup>

The needs for palliative care for dementia are particularly lower than those presented worldwide, but similar when compared to the rest of the American region.<sup>1</sup> This could be due to the underreporting of dementia as a cause of death.<sup>17,18</sup> It is striking that dementia is not identified as a cause of death in the

poorest regions, such as the American and African regions. The data relating to pneumopathies are similar to worldwide publications.<sup>1,9</sup>

In the coastal provinces, heart disease (Guanacaste) and pneumopathies (Limón and Puntarenas) are among the first five causes of death requiring palliative care. These causes are not among the first in the central provinces of the country, even though it is in these areas where most people die from pneumopathies.<sup>19</sup>

Finally, this research represents a first approach to the reality and national needs of palliative care. The methodology used can be improved since it is based mainly on the diagnosis of the disease, there being more complex and difficult to quantify factors that could increase the need for palliative care.<sup>20</sup> However, diagnosis continues to be one of the most frequently used reasons for referrals in these analyses. On the other hand, causes of death often do not adequately reflect the diagnosis of care. For example, dementia,<sup>17</sup> Parkinson's<sup>21</sup>, and nephropathies<sup>22</sup> are frequently underdiagnosed as causes of death, as usually these patients ultimately die from infectious diseases such as bronchopneumonias, urinary tract infections, etc.

Despite this, this first approach that seeks to know the palliative care needs at the national level by province is an invaluable support for the planning of services and the allocation of resources in a fairer, more equitable, and supportive manner.

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