

Palliative Care in Brazil: with a View to Future Needs

ORIGINAL

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Abstract

Introduction: Chronic non-communicable diseases (CNCD) constitute a health problem of growing magnitude in Brazil, leading concerns, to the Ministry of Health (MOH), about the care of persons with chronic conditions (due to advanced diseases), multiple harms and in need of long-term care, requiring continuous assistance,. However, few data exist on the size of the population potentially in need of palliative care in Brazil.

Objective: To estimate the size of the Brazilian population that could benefit from palliative care across 26 federated states and the Federal District.

Methods: This is a cross-sectional study, using national death certificate and hospital admission data. Brazilian death registration and hospital admission data from 1st of January to 31st of December 2014 were analyzed and compared with estimation methods of Rosenwax and Murtagh including all adults (≥ 15 years old) who died in the period of 1st of January to 31st of December 2014 in Brazil.

Results: the proportion of individuals who died from diseases that indicate palliative care needs at the end of life ranged from 24.6% to 85.2%.

Conclusion: Integration of several existing policies, trigger and strengthen actions and integral care to patients with palliative care needs respectful of the specificities of each area as well as to support decision-making and the development of actions in health, in particular to the definition of needs and priorities, the construction of prospective scenarios, and the assessment of ongoing actions.

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Keywords

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Introduction

Ageing of the population translates into a greater disease burden, more incapacities, and increased use of the health services, showing the need to (re) organize the assistance models. The increase in the elderly population can result in a greater number of illnesses and/or chronic conditions that require more medical and social services; besides, hospitalization and length of bed occupancy are greater for them than for other age groups. [1, 2]

The main causes of mortality, among elderly Brazilians, are cerebrovascular disease, heart disease, and diabetes, showing that, in the Brazilian epidemiologic transition, there are situations resulting from disability of preventable risk factors control. [3, 4] In the year 2000, approximately 9% of the population consumed more than 26% of in-patient capabilities in SUS. [1] In 2014, the spending on hospitalizations with the elderly population was 32%, and the expenditure on cases of heart diseases reached 60%. [5, 6]

Non-communicable diseases (NCD) constitute a health problem of growing magnitude in Brazil, leading concerns to the Ministry of Health (MOH), since the end of the 1990s, about the care of persons with chronic conditions (due to advanced diseases).

According to Schmidt et al. [7], 58% of all deaths that occurred in Brazil, in 2007, were related to four NCDs prioritized in the World Health Organization Action Plan, developed for the period of 2008 to 2013 (actions conducted to circulatory diseases, chronic respiratory diseases, diabetes, and cancer were prioritized). [8, 9]

Between 2008 and 2014, circulatory diseases, chronic respiratory diseases, diabetes, and cancer accounted for 52% of the total deaths recorded in the Brazilian Mortality System (SIM-DATASUS) [10], who were related to four NCDs prioritized in the World Health Organization Action Plan.

According to the Brazilian Ministry of Health, NCDs: 1) present a gradual onset that usually does

not lead to a cure, lasting a long or an uncertain time; 2) in general present multiple causes; and 3) require a treatment that involves lifestyle changes, in a process of continuous care. Hence, people with chronic, advanced or life-limiting diseases, whatever their diagnosis, should have equal access with appropriate management of their physical, psychological, social or spiritual needs as well as access to diagnostic and therapeutic resources in a timely manner, in order to ensure the completeness of the necessary care to the user's health, in all levels of health care system. [11]

More recently, the Brazilian MOH, recognizing the demographic and epidemiologic transition and the increased prevalence of chronic diseases with the ageing of the population and its impact on the health of the elderly, have reset the health care network for people with chronic diseases and have established guidelines for the organization of their care. [12]

Palliative care has been considered, by the World Health Organization (WHO), as "an urgent humanitarian need worldwide for people who have serious illnesses such as cancer and other incurable diseases". [13-16] The 67th World Health Assembly Resolution of May 2014 recommended integrate palliative care in all healthcare settings for all member countries. [17]

However, demographic changes associated with fast ageing population, longer chronic disease trajectories, and greater co-morbidities require further incentives to improve and expand palliative care provision. [18, 19]

The Brazilian National Health System faces major challenges to ensure the constitutional right of universal access to health care assistance and technological advances to the entire population. Concerns with the ageing population, the increasing incidence of cancer, and the emergence of chronic diseases include palliative care as one of the objectives of the National Health System. In the last decades, several initiatives, by the Ministry of Health, have incorpo-

rated palliative care as an important strategy for the health policy. [20-25] (**Table 1**)

Traditionally, palliative care in Brazil has been offered most often to people suffering from cancer in advanced stage, and the care needs for people who have other life-limiting chronic diseases are not being fulfilled in a stable approach. The conception of propounding palliative care, only at the end of life, limits the access to many people and carers that could benefit from this mode of health assistance during the trajectory of the disease; from diagnosis, continuing to benefit from treatments that alter the progress of the disease, until the end of life. [26]

Despite the fact that the palliative care structures and resources have had a significant increase in recent years in Brazil, the distribution of services are concentrated in some regions and the health care for people with chronic advanced or life-limiting diseases is fragmented and also exist differences in the level of access and kind of care. [26]

Regarding cancer, data from DATASUS shows that, in 2014, cancer was responsible for 200,979 (15.6%) of all deaths in Brazil. [27] In contrast, there is no specific estimates of palliative care needs and structure in the country that meets the existing demand. There is a minimum supply of specialized hospital beds, which is restricted to the big cities. Thus, the condition in which the deaths due

to cancer occurred and continue to occur should be considered. [26, 28, 29] Nowadays there is also an increasing awareness that palliative care is not only for patients with incurable cancer but also for patients with chronic obstructive pulmonary disease (COPD), heart failure or dementia, for instance. [18, 30]

The quantification of the needs of palliative care in Brazil has been carried out, taking as a basis parameters used in countries with tradition in this health care model. However, there are doubts about the applicability, in our country, of these parameters based on studies and international experiences, considering the population and territorial dimensions as well as the regional diversities.

It becomes essential to know the size, nature, and severity of the needs of people with regard to access to health services as well as to identify the availability of resources to promote full assistance of people with advanced progressive chronic diseases in our country.

The objective of our study was to identify a feasible population-based method to estimate the number of people who would benefit from palliative care health services in a Brazilian population. From a series of estimations to get an idea of how many people may be in need of palliative care, it is possible to build a baseline for health system planning and palliative care needs in cancer and non-cancer patients.

Table 1. Prognosis and trajectory of chronic diseases.

Group of diseases	Disease trajectory	Prognosis/course of illness
Cancer	Steady progression Clear terminal phase	Predicted
Respiratory and heart failure	Gradual decline Episodes of acute deterioration Sudden/unexpected death	Live longer with more disability Die suddenly with little warning after rapid deterioration
Dementia	Prolonged gradual decline	Live for a long time Increasingly dependent Distressing for their families

Source: Murray et al. [18]

Methods

This research presents a quantitative approach, with descriptive, exploratory, retrospective and observational studies of national mortality data, which were derived from the National Mortality System of the National Health System (SIM – DATASUS). The mortality population-based database, published every two years, contains information on the cause of death as well as sex and age. The cause of death is coded using the ICD-10-WHO (**Tables 2, 3, 4**).

Table 2.

Group of diseases	MacNamara & Rosenwax [32] - Australian estimative	Murtagh [33] -British estimative
Cancer	C000-D489	C000-C979,
Respiratory system	J40, J410, J411, J418, J42, J43 J431, J432, J438, J439, J440, J441, J448, J449	J060-J129, J13, J14, J150-J189, J200-J219, J22, J40, J410-J419, J42, J430-J459, J46, J47, J960-J969,
Circulatory system	I500, I501, I509, I111, I130, I132	I000-I529, I600-I699,
Renal system	N180, N188, N189, N102, N112, N120, N131, N132	N180-N189, N280-N289, N17, N170-N179
Hepatic system	K704, K711, K721, K729	K70-K77
Nervous system	G300, G301, G308, G309; G20, G200; G122; G10, G100	G122, G20, G200, G10, G100, G35, G903, G231, F010-F019, F03 G300, G301, G308, G309, R54
HIV/AIDS	B200-B249	B200-B249

All simulations were performed taking as a basis the registered deaths in the period from 1st of January to 31st of December 2014 in Brazil, based on the ICDs that each of the mentioned studies considered as liable to palliation. From this survey, and using as a basis the study of Scholten et al. [31], which compares MacNamara & Rosenwax methods with Murtagh methods, we identified the minimal and maximal estimates, because we found the same problem to identify mid-range estimates of palliative care needs as described in the Germany study. [31] In Brazil, we also cannot match the general mortality statistics with data from hospital admission. [32, 33-36]

Based on the study of Scholten et al. [31], "The size of the population potentially in need of palliative care in Germany – an estimation based on death registration data", we adapted the Brazilian mortality data registered in 2014 to the MacNamara & Rosenwax and Murtagh methods.

Table 3.

Non-communicable diseases/Brazilian estimative	
Cancer (all types)	C000-C979
Cardiac disease	I00-I999
Respiratory diseases	J30-J989
Diabetes mellitus	E10-E149
Other chronic diseases	D00-D489, D55-D648, D65-D899, E03-E079, E15-E169, E20-E349,
	E65-E889, F01-F999, G06-G989, H00-H619, H68-H939, K00-K929, N00-N649, N75-N989, L00-L989, M00-M999, Q00-Q999

Table 4.

Seven causes	
Cancer	C000-D489
Diabetes mellitus	E10-E149
Alzheimer's disease	G300, G301, G308, G309
Cardiac diseases	I25, I24, I50
Cerebrovascular disease	I60-I69
Respiratory diseases	J40-J47
Hepatic disease	K70-K77

Source: Californian estimative Kerr et al. [35]

Results

The first quantification of the needs of palliative care in Brazil was done at least a decade ago. Study conducted by Maciel and Betega [36], using national mortality data recorded in 2004, was related to international parameters to estimate population with palliative care needs in Brazil.

In 2004, 1,024,073 deaths were registered in Brazil, being the first cause cardiovascular diseases, with 285,543 (27.9%) deaths; followed by neoplasms, with 140,801 (13.7%) deaths; external causes, with 127,470 (12.4%) deaths; and respiratory diseases, with 102,168 (10%) deaths. In the study, the leading causes of death were grouped, with the exception of maternal and external causes, resulting in 528,512 causes supposedly amenable to palliation.

In 2014, 1,227,039 deaths were registered in Brazil: cardiovascular diseases, with 340,284 (27.7%) deaths; followed by neoplasms, with 201,968 (16.5%) deaths; external causes, with 156,642 (12.8%); and

Table 5. Quantification of the needs of palliative care in Brazil (2004 and 2014) .

Year	Population (million hab)	Total mortality	Cardiovascular diseases	Cancer	Respiratory diseases	External causes
2004	182,9	1,024,073	285,543 (27.9%)	140,801 (13.7%)	102,168 (10%)	127,470 (12.4%)
2014	202,8	1,227,039	340,284 (27.7%)	201,968 (16.5%)	139,045 (11.3%)	156,642 (12.8%)

Source: National Mortality Information System of SUS (SIM – DATASUS) [10]

respiratory diseases, with 139,045 (11.3%) deaths, resulting in 681,297 (55.5%) causes with indication of palliative care. In conclusion, between 2004 and 2014, the needs of palliative care had an increase of 28.9% in Brazil (**Table 5**).

During 2014, according to the SIM – DATASUS, 1,227,039 deaths were registered in Brazil, being the death rate up to 6,038.58 per million of inhabitants per year. The leading causes of death were the diseases of circulatory system, with 340,284 (27.7%) deaths; followed by cancer, with 201,968 (16.5%) deaths; external causes, with 156,942 (12.8%) deaths; respiratory diseases, with 139,045 (11.3%) deaths; diabetes, with 57,882 (4.7%) deaths (**Figure 1**).

Considering the four main causes of death registered in Brazil in 2014, with the exception of external causes, the number of people who could benefit from palliative care was 667,090 (54.35%) of the total deaths. The following estimation of the number of people who were possibly in need of palliative care for the year 2014 was based on methods of MacNamara & Rosenwax (minimal and maximal estimations), Murtagh and simulations of Kerr (Seven causes) and Brazilian Ministry of Health (Non-communicable diseases) (**Table 6**).

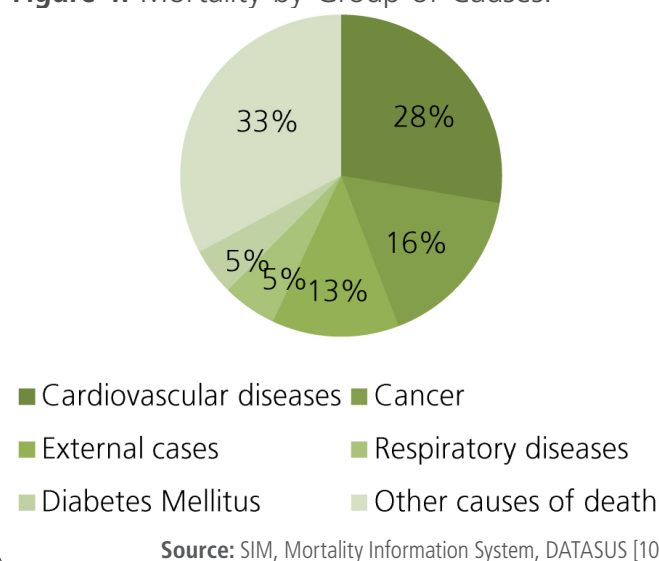
According to the method of MacNamara & Rosenwax:

1. The total number of deaths potentially in need of palliative care was 301,951 (25%).
2. Cancer accounted for 67% of all deaths with indication of palliative care.

Through the method of Murtagh:

1. The total number of deaths potentially in need of palliative care was 702,195 (57%).

Figure 1: Mortality by Group of Causes.



2. Cancer accounted for 28% of all deaths with indication of palliative care.

Through the method of Seven Causes:

1. The total number of deaths potentially in need of palliative care was 490,152 (39.9%).
2. Cancer accounted for 41% of all deaths with indication of palliative care.

Through the method of NCD:

1. The total number of deaths potentially in need of palliative care was 839,946 (68.5%).
2. Cancer accounted for 24% of all deaths with indication of palliative care.

The method of Murtagh is almost 2.3 times more people compared to the method of MacNamara & Rosenwax. The proportion of patients in need of palliative care because of a cardiac insufficiency disease rises from 9% (MacNamara & Rosenwax) to 46% (Murtagh), making cardiac insufficiency disease the most frequent underlying cause for the potential demand of palliative care.

Table 6. Comparison of the methods studied.

Group of diseases	Estimation methods			
		Murtagh	Seven Causes	NCD
Cancer	201,968 (16.5%)	198,308 (16.2%)	201,968 (16.5%)	198,308 (16.2%)
Cardiac disease	28,205 (2.3%)	323,820 (26.4%)	46,705 (3.8%)	340,284 (27.7%)
Respiratory diseases	39,795 (3.2%)	118,389 (9.6%)	42,222 (3.4%)	66,956 (5.5%)
Diabetes mellitus			57,882 (4.7%)	57,882 (4.7%)
Cerebrovascular disease			99,289 (8.1%)	
Renal insufficiency	6,363 (0.5%)	6,758 (0.6%)		
Hepatic disease	3711 (0.3%)	26,368 (2.1%)	26,368 (2.1%)	
HIV/AIDS	1,640 (0.1%)	1,640 (0.1%)		
Degenerative diseases		26,912 (2.2%)		
Motor neuron disease	1,110 (0.1%)			
Huntington's disease	87 (0.007%)			
Alzheimer's disease	15,718 (1.3%)		15,718 (1.3%)	
Parkinson's disease	3,354 (0.3%)			
Others cronic disease				176,516 (14.4%)
Total deaths indicating palliative care	301,951 (24.6%)	702,195 (57.2%)	490,152 (39.9%)	839,946 (68.5%)
Total deaths 2014	1,227,039			
Estimates of palliative care needs	24.6%	57.2%	39.9%	68.5%

Source: Adapted by the authors of the estimates of MacNamara et al. [32]; Murtagh et al. [33] and Scholten et al. [31].

The MacNamara's & Rosenwax's minimal estimate identifies 24.6% of all deaths eligible for palliative care, and Murtagh's adaption of the method of MacNamara & Rosenwax for a minimal estimate expands the demand to 57.2% of all deaths. Simulations of settings were used to adapt and match the Brazilian mortality data with MacNamara & Rosenwax and Murtagh methods, searching to identify the proportion of individuals that could benefit from palliative care in the last year of life. A maximal estimate defined by MacNamara et al. [43] and Murtagh et al. [33] included all deaths, except external causes and maternal, neonatal or perinatal deaths. A total of 1,045,726, accounting for 85.2% of all deaths, could be potential palliative care patients (maximal estimate).

Based on the update of the first study conducted in Brazil for the estimate of palliative care population (Maciel and Bertega [36]), a study that can be

considered as the national baseline of palliative care needs, we observed that, in 2014, of the total cases of death recorded in the Mortality Information System of SUS, 681,297 (55.5%) are cases of patients who should have received palliative care.

By relating the updated estimate of Maciel and Bertega [36] to the simulations of the methods of MacNamara et al. [32], Rosenwax et al. [34], Murtagh et al. [33], Kerr et al. [35] and the Brazilian Ministry of Health [27], we verified that the need for palliative care is closer to the Murtagh's method.

Discussion

Several studies have been carried out for the estimation of population with palliative care needs, [32, 33, 37-40] In this research, we compare different studies with national and international parameters related to deaths caused by groups of diseases that

would require palliative care: MacNamara et al. [32], Murtagh et al. [33], Rosenwax et al. [34] Kerr et al. [35], Maciel and Bertega [36], and the Brazilian Ministry of Health [27].

Chronic diseases usually do not come alone and, often, add up to cause many problems affecting the quality of people's lives. The uncertainty of prognosis in the trajectories of advanced chronic diseases, other than cancer, can give the impression that it will be more difficult to plan the structures of health services. Murray et al described three distinct trajectories of groups of diseases for people with progressive chronic illnesses (**Table 1**). [18]

Health care planning in Brazil is based, since the beginning of the 1980s (1982), on technical parameters intended to estimate the health needs of the population. The parameters of the Brazilian Health System, which are considered as assessment tools, also offer fundamental supports for the scaling of the assistance coverage, the productivity of health services, and the capacity of the existing services. [41-44]

However, despite the increasing ageing population, the rise of the incidence of cancer, and the emergence of chronic non-communicable diseases, which enhance the need for this type of care in the country, and the fact that the Brazilian Ministry of Health (MOH) includes palliative care as one of the objectives of the National Health System, no data on the size of the population in need of palliative care exist. [45, 46]

Within the framework of chronic diseases, malignant cancer deserves a differentiated approach, for its high incidence and prevalence, its consumption of large amounts of financial resources, and its big institutional and social burden. [47-49]

However, as a commitment, international policies have been holding discussions about the expansion of this form of assistance for those people who live with cancer and other chronic non-communicable diseases (CNCD), and this expansion has already started. [28]

To analyze the Brazilian standards of mortality, one might think that the country went through an accelerated process of epidemiological transition, based on the reduction of the participation of communicable diseases and the increased participation of non-communicable diseases (NCD). Demographic and epidemiological changes occurring in Brazil are pointing to the idea that, in the next few years, the number of deaths by non-communicable diseases will increase mainly through the group of elder patients with chronic and/or degenerative diseases that frequently course a long stage, pointing an indication of palliative care. [50]

It is internationally recognized that, when applied early, palliative care brings benefits for patients and their families through the promotion of better quality of life. In addition, palliative care decreases the hospital length of stay, the re-hospitalization, the futility therapeutic, the admission in emergency rooms, and intensive care and, consequently, decrease health costs. However, a public health perspective is required to address the challenges to measure the palliative care needs and the distribution of these needs within the population (who could be benefited). A strategy to determine this population is the definition of feasible parameters for estimating palliative care needs in our country.

Taking as an example the Strategic Plan for the Development of Palliative Care in Portugal for the period of 2016 to 2017, which relates the chronic diseases to the increase in life expectancy and the limitation of resources for expansion of the network of palliative care services, we should promote a reflection on the model of existing health care assistance, know the size, nature and severity of the needs of people with regard to palliative care as well as to establish the differentiation between different levels of care. [51]

Conclusion

We propose guidelines based on integration of several existing policies, trigger and strengthen actions and integral care to patients with palliative care needs that are synergistic, sustainable and respectful of the specificities of each area as well as to support decision-making and the development of actions in health, in particular to the definition of needs and priorities, the construction of prospective scenarios, and the assessment of ongoing actions.

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