## Death in hospital and at home: population and health policy influences in Londrina, State of Paraná, Brazil (1996-2010)

Fernando Cesar Iwamoto Marcucci 1 Marcos Aparecido Sarria Cabrera 1

> **Abstract** An aging population and epidemiological transition involves prolonged terminal illnesses and an increased demand for end-stage support in health services, mainly in hospitals. Changes in health care and government health policies may influence the death locations, making it possible to remain at home or in an institution. The scope of this article is to analyze death locations in the city of Londrina, State of Paraná, from 1996 to 2010, and to verify the influence of population and health policy changes on these statistics. An analysis was conducted into death locations in Londrina in Mortality Information System (SIM) considering the main causes and locations of death. There was an increase of 28% in deaths among the population in general, though 48% for the population over 60 years of age. There was an increase of deaths in hospitals, which were responsible for 70% of the occurrences, though death frequencies in others locations did not increase, and deaths in the home remained at about 18%. The locations of death did not change during this period, even with health policies that broadened care in other locations, such as the patient's home. The predominance of hospital deaths was similar to other Brazilian cities, albeit higher than in other countries. Key words Mortality, Causes of death, Home

care, Death location, Palliative care

<sup>&</sup>lt;sup>1</sup> Departamento de Saúde Coletiva, Universidade Estadual de Londrina. Rod. Celso Garcia Cid Km 380, Campus Universitário. 86057-970 Londrina PR Brasil. fcim@msn.com

#### Introduction

In the past century, there has been a change in the treatment of health problems, shifting from informal care associated with philanthropic institutions to the predominance of healthcare services provided by medical clinics and hospitals. The technical improvements in healthcare directed the treatment of various diseases to specialized services and, together with the social and economic development, opened the possibility of hospital care at the end of life to a larger number of patients. Therefore, the process of dying and death itself became institutionalized and ceased to occur at home, moving instead to the hospital setting<sup>1-3</sup>.

The World Health Organization estimates that, by the year 2030, the most frequent causes of death will be chronic noncommunicable diseases (NCDs), including cancer, cardiovascular and cerebrovascular diseases, and chronic lung diseases, among others, which often involve a prolonged end-of-life period, causing a decline in the quality of life of patients long before the occurrence of death<sup>3-5</sup>. The Brazilian population, in this social and demographic context, has experienced increased longevity and increased prevalence of NCDs among the causes of death, and the southern region of Brazil has the largest number of older inhabitants<sup>6</sup>.

The prolonged end-of-life process resulting from NCDs leads to prolonged suffering by the patients and caregivers and involves decisions concerning routine changes, management of health expenses, and choices associated with the end of life, including the adoption of invasive measures and the place of death. A systematic review by Gomes et al.5 involving 210 studies from 34 countries analyzed the preference for the place of death of 100,307 patients. These authors found a strong preference for dying at home when there is availability of adequate support for the demands of patients. In 75% of the studies included in this review, more than 50% of the respondents expressed a preference for dying at home, and in one third of the studies, this preference was expressed by more than 70% of the respondents. However, the place of death is not always a matter of choice and depends on the risks and limitations of the options provided by healthcare services.

At present, Londrina is a regional reference in healthcare. Londrina has a large hospital network and was one of the first municipalities in Brazil to develop a home care system in 1996, which included a team focused on palliative care, particularly for cancer patients<sup>7</sup>. In addition, some public

policies, such as the National Program for Pain and Palliative Care (2002) 8, the National Policy of Oncology Care (2005)9 and Ordinance No. 2529 of October 19, 2006, which established home care in SUS<sup>10</sup>, may have influenced the characteristics of the dying process among the population, directing the occurrence of death to the home environment.

To assess the characteristics of deaths in this population, especially with respect to the place of occurrence, this study aimed to analyze population data from this municipality in recent years and to discuss the status and the influence of public policies in the end-of-life process.

#### Method

This descriptive epidemiological study used information obtained from the public database of the Mortality Information System (Sistema de Informações sobre Mortalidade-SIM)11. A search of the annual deaths in the population living in the city of Londrina between 1996 and 2010 was conducted, considering causes of death (defined by the chapters of the International Classification of Diseases, 10th revision - ICD-10) and the places of death (hospital, other health facilities, home, public roads, other places, and unknown places). The search was conducted through 2010, which was the last year available in the database at the time the study was conducted. Data analysis allowed a comparison of the places of death, classification of the main causes of death, and evaluation of the annual progression of these variables.

In addition, studies on this subject involving the study population were searched in the SciELO, PubMed, and Lilacs databases using the following keywords to compare the frequencies of the places of death in different populations: "Cause of Death", "Mortality", "Hospital Mortality", "Home Care" and "Place of death", The search in the SIM database and in the remaining databases was conducted for the period between May and December 2013.

#### Results

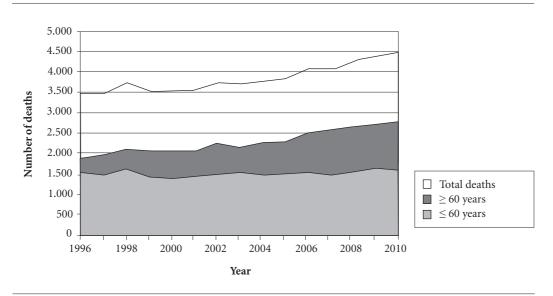
The SIM database search revealed a gradual annual increase in the number of deaths from 3,478 occurrences in 1996 to 4,467 occurrences in 2010 (28% increase), as well as an increase of 48% among the population above 60 years (Figure 1). Individuals above 60 years accounted for 60.3%

of all deaths in this period, followed by those aged between 15 and 59 years (33.2%), those aged between 1 and 14 years (2.0%), and those less than 1 year (4.4%).

The analysis of the annual progression per place of death revealed a gradual and significant increase in the number of occurrences in hospitals starting in 2006. However, this increase was not observed for deaths at home and on public roads in this municipality (Figure 2).

With respect to the distribution of the places of deaths in the municipality, more than 70% of the deaths occurred in hospitals, and approximately 18% occurred at home on average during the study period (Table 1).

The main causes of death were diseases of the circulatory system (31%) and cancer (19%), followed by external causes and respiratory diseases. Figure 3 presents the influence of the causes of death in the annual progression of hospital and



**Figure 1.** Progression of deaths among the population older and younger than 60 years in Londrina state of Paraná (1996–2010).

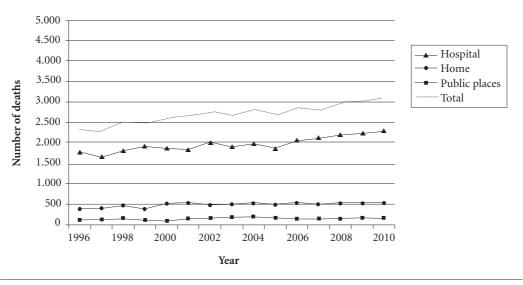


Figure 2. Progression of deaths in Londrina by place of occurrence (1996–2010).

home deaths. Cancer exhibited a more significant contribution to the increase in the number of hospital deaths in the last five years, whereas deaths due to circulatory diseases remained relatively stable.

With regard to the place of death due to circulatory diseases, the average frequency of hospital and home deaths corresponded to 72.56 (SD = 3.50%) and 23.07 (SD = 3.78%) of all deaths from this cause, respectively. Hospital deaths due to cancer corresponded to 82.08 (SD = 4.07%) of all deaths from this cause on average, indicating

an increase of approximately 200 cases per year between the first and last year, whereas home deaths remained stable, corresponding to 16.66 (SD = 3.24%) of the total deaths from this cause on average.

#### Discussion

Londrina is located in the northern region of the state of Paraná and has a population of 506,701 inhabitants according to the 2010 Population

Table 1. Percentage distribution of home deaths in Londrina (1996–2010).

Year	% Hospital	% Home	% Public places	% Other
1996	76.07	16.05	5.41	2.47
1997	73.45	17.64	5.92	2.98
1998	72.27	18.51	5.88	3.34
1999	77.23	15.86	4.26	2.65
2000	71.29	19.92	4.85	3.59
2001	70.41	20.07	5.03	4.49
2002	73.41	17.36	6.57	2.65
2003	71.31	18.80	6.74	3.15
2004	70.62	18.61	7.13	3.64
2005	69.42	18.35	6.19	6.04
2006	72.84	18.66	5.43	3.07
2007	75.20	17.15	5.16	2.49
2008	74.05	17.46	5.56	2.93
2009	74.24	16.99	5.68	3.09
2010	74.06	17.31	5.58	3.06
Mean	73.06	17.92	5.69	3.31
Standard deviation	2.20	1.23	0.75	0.92

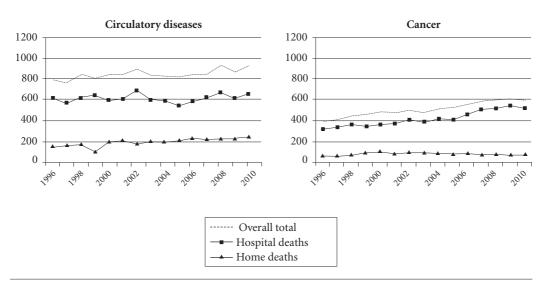
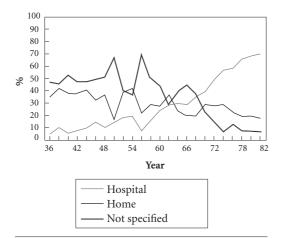


Figure 3. Annual incidences of death from circulatory disease and cancer in Londrina (1996-2010).

Census<sup>12</sup>. Londrina is the second most populous city in the state of Paraná, and its healthcare structure is reference for the other municipalities in the region. The city, founded in 1934, underwent a relatively recent urban development starting in the 1960s, and the population growth together with the increased demand for healthcare required the structuring of the hospital network. The way the regional development affected the characteristics of the deaths in the municipality was detailed in the study by Laprega and Manço, who recorded the number deaths between 1936 and 1982 in two-year intervals. An overlay of plots using data from the resident population reveals the transition of the place of death and the improvements in the data collection system<sup>1</sup> (Figure 4).

An inversion in the place of death was observed in Londrina, which moved from the home setting to the hospital setting starting in the mid-1960s. In the 1980s, the frequency of hospital deaths was approximately 70%, which remained stable in this 15-year period, as observed in the present study.

In addition, the increased number of deaths in the older age groups was due to population aging associated with the epidemiological transition, with a predominance of non-transmissible diseases as the major causes of death. End-of-life hospitalization is a common situation in modern-day society. This situation may occur owing to the technical and scientific requirements applicable to cases in which the patient is at the end



**Figure 4.** Percentage of hospital and home deaths among residents of Londrina, state of Paraná (1936–1982) (overlapping of plots from Laprega and Manço, 1999¹).

of life. This fact, together with prolonged human longevity and the epidemiological transition with a predominance of non-infectious diseases, demands a constant increase in the number of hospital beds, intensive care units, and staff<sup>5,6</sup>.

In 1996, Londrina structured a home care system that included a team focused on palliative care, particularly for cancer patients<sup>7</sup>. The availability of palliative care at home has been strongly associated with the possibility of dying at home<sup>13</sup> and allows greater freedom of choice for patients and caregivers, helping them to focus on the quality of life at the end of life. However, several factors limit the occurrence of death at home, including the need for frequent medical visits, the availability of support staff, limitations of or poor acceptance by family members, and clinical conditions (e.g., pain and difficult-to-manage symptoms)<sup>13</sup>. In the absence of adequate support, the occurrence of death at home can be stressful or traumatic for those involved in the process.

Therefore, despite the fact that local initiatives and national policies have extended the possibility of death to the home setting, no changes were observed in the frequency of home deaths. Rather, the increase in the number of deaths was observed primarily in the hospital setting.

#### The place of death in different contexts

Despite the increased prevalence of hospital deaths, many countries have attempted to decrease this prevalence through specific public policies to improve the quality of death and decrease the costs involved. Since the 1980s, economically developed countries have reported a decrease in hospital deaths due to cancer (for the patients who are most often referred to hospitals to receive palliative care) and due to other causes. These deaths were not correlated with the increase in the number of home deaths but with the increase in the number of available beds in specialized long-term care facilities (LTCFs), such as hospices and care homes 14.

A study conducted by Gao et al.<sup>15</sup> analyzed the places of death due to cancer in England between 1993 and 2010 and found that the proportion of hospital deaths decreased from 49% to 44.9% in this period, whereas home deaths remained stable, varying between 22.4% and 26.2%. Another frequent place of death in England is hospices, which increased their participation from 13.6% to 17.4% between 1993 and 2010. These authors correlated the partial decrease in the frequency of hospital deaths to a national end-of-life care pro-

gram conducted in England starting in 2004. This program attempted to meet the preferences of the patients with respect to the place of death according to the specific care required by these patients.

For the Belgian population, Houttekieret al. <sup>14</sup> found that between 1998 and 2007, the percentage of hospital deaths decreased from 55.1% to 51.7%, whereas deaths in care homes increased from 18.3% to 22.6%. The home deaths remained relatively stable over the studied period, ranging between 22.4% and 23.0%. According to these authors, the decrease in the proportion of hospital deaths was due to the replacement of home beds for beds in care homes. Furthermore, by considering the progression of the observed trends, the authors estimated that deaths in care homes may reach or even exceed hospital deaths by the year 2040.

Considering the Brazilian context, the high rate of hospital deaths was also observed in other regions, as in the study by Telarolli Junior and Loffredo<sup>6</sup> conducted in Araraguara, state of São Paulo in the period 2006-2011 involving individuals above 60 years. These authors reported a percentage of 76% of hospital deaths and 20% of home deaths. Deaths in nursing homes and hospices have increased but are still modest considering the overall distribution (less than 4%). The main causes of death were very similar to those found in the present study, with a predominance of noncommunicable diseases. The higher frequency of home deaths was attributed to a greater willingness to consider home death as an option for older people to humanize the event.

A study conducted in Recife between 2004 and 2006 involving patients 60 years or older reported that the frequency of hospital deaths varied between 75.5% and 82.2%, whereas home

deaths varied between 16.1% and 19.5% and LTCFs accounted for less than 2%. The authors observed a higher probability of hospital deaths in the strata with poor living conditions, suggesting that those with limited resources have limited access to hospitals in the early stages of the disease and are referred to the hospital at later stages, thereby limiting the healthcare received in more advanced phases<sup>16</sup>.

A comparison of the frequency of places of deaths in different populations is presented in Table 2.

# Brazilian policies and their relationship with the place of death

Hospitalization rates are believed to be determined by public health policies, the availability of hospital beds, and home care support<sup>13</sup>. In the Brazilian context of end-of-life care, the possibilities are limited and focused on hospital deaths, with a minimal amount of home deaths, which results in overcrowding in hospitals<sup>17,18</sup>.

At present in Brazil, no additional options are available to the population, especially in the public sector, such as LTCFs specialized in the care of advanced stage patients (such as hospices) or structured palliative care services. Resolution No. 283 of the Board of the National Health Surveillance Agency (Agência Nacional de Vigilância Sanitária–Anvisa) of 26 September 2005 established the acceptable parameters of care provision and the physical and operational structure of human resources for the establishment of LTCFs for older people. However, it did not establish the healthcare conditions for advanced-stage patients, access for non-elderly but dependent individuals, and those in need of palliative care<sup>21</sup>.

**Table 2.** Percentage of deaths according to the place of occurrence in different countries and Brazilian municipalities compared with the present study.

Country	Period	Hospital deaths	Home deaths	LTCF deaths	Author, year
England	1993 a 2010	49%-44.9%	22.4%-26.2%	13.6%-17.4%	Gao et al., 2013 <sup>15</sup>
Belgium	1998 a 2007	55.1%-51.7%	22.4%-23.0%	18.3%-22.6%	Houttekier et al., 201214
Germany	1994 a 2009	44%-50%	29%-38%	13%-21%	Simon et al., 201219
Canada	1994 a 2004	77.7%-60.6%	19.3%-29.5%	3.0%-9.9%	Wilson et al., 200913
United States	1980 a 1998	54%-41%	17%-22%	16%-22%	Flory et al., 2004 <sup>20</sup>
Brazilian municipalities					
Londrina	1996 a 2010	76.79%-82.66%	10.93%-17.01%	$0.24 – 0.7\%^{\beta}$	*
Araraquaraα	2006 a 2011	76%	20%	>4%	Telarolli Júnior e
					Loffredo, 20136
Recife <sup>α</sup>	2004 a 2006	75.5%-82.2%	16.1%-19.5%	>2%	Magalhães et al., 201116

 $<sup>^\</sup>beta Data$  available only from 2000.  $^{^\circ} Data$  from the present study.  $^\alpha Data$  from individuals above 60 years.

In recent years, the alternative to hospitalization promoted by the public sector is home care. In the Unified Health System (Sistema Único de Saúde - SUS), this healthcare delivery model was established by Law No. 10,424 of April 15, 2002, which defined home care, including hospitalization, with respect to preventive, therapeutic, and rehabilitative medicine<sup>22</sup>. In addition, through Ordinance No. 2,529 of October 19, 2006, other measures were defined, including those involving operational aspects, training of healthcare teams, definition of financial resources and accreditation conditions. These measures prioritized older people, those with exacerbated chronic degenerative diseases, carriers of diseases that require palliative care, and patients with either temporary or permanent functional disabilities<sup>10</sup>. More recently, the modalities of home care were redefined by Ordinance No. 963 of May 27, 2013<sup>23</sup>, which established Home Care Service (Serviço de Atenção Domiciliar-SAD) in the SUS. This ordinance also defined the training required by the Multidisciplinary Home Care Team (Equipe Multiprofissional de Atenção Domiciliar-EMAD) and included palliative care and end-oflife care in its prerogatives and was later supplemented by Ordinance No. 1,208 of June 18, 2013, which integrated the Best at Home ('Melhor em Casa') Program (Home Care as part of SUS) with the SOS Emergency Program<sup>24</sup>.

With regard to specific care, Ordinance No. 19 of January 3, 2002 established the National Program for Pain and Palliative Care but did not define the forms of implementation8. Ordinance No. 2439 of December 8, 2005 instituted the National Policy for Oncology Care, which highlighted the need to integrate the various levels of care, including palliative care, for the treatment of cancer patients. This ordinance establishes the possibility of conducting palliative care in addition to preventive and therapeutic actions for these patients through the primary healthcare system9. In addition, policies targeted specifically to the rights of older people are in force, including the Statute of the Elderly and the National Health Policy for the Elderly. However, their effectiveness depends on the participation of agents (users, professionals, and managers) to ensure increased support for the care of the growing elderly population<sup>25</sup>.

Despite the demographic trends and the increased prevalence of chronic diseases, many healthcare systems remain focused on immediacy, with emphasis on acute care rather than on preventive and chronic care, and healthcare ser-

vices continue to treat chronic diseases as isolated episodes<sup>26</sup>. In these cases, the occurrence of death can be predicted in advance, and the healthcare actions should promote the attainment of a dignified death, which involves increased access to palliative care, more choices for the place of death, and technical support to family members, even in the home setting.

#### **Final Considerations**

The results of this study indicated a predominance of deaths in hospitals and were similar to those observed in other Brazilian cities, but the frequencies reported herein were higher than those obtained in other countries. It was also possible to observe the increased influence of population aging and noncommunicable diseases in the death process, which was directed to hospital care at the end of life. One should consider that, with respect to the end-of-life care, it is not only the death event that matters but the whole process of dying<sup>27</sup>. Therefore, rather than the place of death, the quality of care and support provided will affect how death will occur for those facing a life-threatening condition and will be remembered by caregivers as either positive or negative experiences.

Among the alternatives to hospitalization, the Brazilian public health policies attempt to expand the number of home beds and the inclusion of palliative care measures for those with advanced-stage diseases or without the possibility of healing. As an alternative, some countries have adopted the expansion of non-hospital institutions, including hospices and care homes, adapted to receive these patients at a reduced operational cost and aimed at creating a more comfortable environment for patients and their families. This model can be considered an alternative for the structuring and expansion of end-of-life care through SUS. Recent changes in public health policies in Brazil can affect the distribution of the places of death and should be analyzed in future studies to assess the quality of death available to the population.

### Collaborators

FCI Marcucci and MAS Cabrera participated in the planning, development, and writing of the manuscript.

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