

User profiles with palliative care needs linked to a primary healthcare center in the city of Porto Alegre, RS

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Abstract

Strengthening in Palliative Care (PC) in Primary Healthcare (PHC) increases the quality of care at the end of life and reduces complications from long hospitalizations. The objective of this work was to analyze data on mortality that occurred in patients with advanced chronic non-communicable diseases associated with the Vila Floresta Primary Healthcare Center of the Conceição Hospital Group (VFPHC-CHG) and to verify how many of these would be eligible to PC. It is a transverse, descriptive and quantitative and retrospective approach research. Data come from electronic health records, management monitoring report, VFPHC-CHG medical records and Porto Alegre Epidemiological Surveillance. The *Palliative Care Screening Tool* (PCST) scale for PC eligibility criterion. Out of a total of 155 people who died and lived in the VFPHC-CHG covered territory in 2019, 55.2% (n = 86) were female, 54.2% (n = 84) were elderly and more 80 years old, 23.9% (n = 37) had died within five years after diagnosis, in 69.7% (n = 108) of cases the place of death was the hospital, 66.5% (n = 103) had no medical record, were neoplasms the main causes of death in 34.8% (n = 54), and 42.6% (n = 66) were considered eligible for PC according to PCST. It is concluded that the profile of people with diagnosis for over five years of the disease that resulted in death could be observed more carefully by PHC teams regarding PC, increasing the search for those who are eligible and establishing effective communication with hospitals in care transfer.

Keywords: Palliative care. End-of-Life Palliative Care. Chronic diseases.

INTRODUCTION

Chronic Non-Communicable Diseases (CNCD) are responsible for 63% of global deaths and are the largest contributors to morbidity and mortality in the world¹. They are pathologies of multiple etiologies, mainly comprising circulatory diseases, cancer, diabetes, pulmonary diseases, and neurolo-

gical diseases which characterize the “epidemiological transition” that encompasses population aging and change in the morbidity and mortality pattern that affects the population².

It is known that the elderly population increased 4.8 million in the period between

2012 and 2017 and that there is a tendency for aging of the Brazilian population³. Projections indicate that in the year 2060 more than one third of the Brazilian population will be composed of people 60 years old or more⁴. In Brazil, in 2019, 54.7% of the causes of death were related to CNCDs and more than 54 million people (45% of the adult population) live with any of these comorbidities^{1,5}. Increased chronic diseases is due to population aging and makes the knowledge and dissemination of palliative care (PC) and end-of-life in primary health-care (PH) more relevant.

The definition of PC states that all individuals who have suffered from serious life-threatening diseases should receive palliative care to improve their quality of life, including family and caregivers^{6,7}. This care is characterized by a multidisciplinary approach that attempts to treat pain and other physical symptoms, as well as the prevention and relief of suffering, and dealing with social, psychological, and spiritual issues. It does not accelerate or slow death, affirm life, and recognize death as a natural process⁷.

The main policy of Brazilian PH is the advancement of preventive actions and health promotion interventions, chronic disease management, and community care⁸. These actions are associated with a decrease in CNCd hospitalization rates. However, the lack of a specific policy aimed at palliative care gives Brazil a low end-of-life care rate, poor access to PC services, and high occurrence of deaths in hospital environments when compared to other countries⁸. In a study that compared the quality of death and dying in 81 countries, Brazil was in position number 79⁹. In addition, it was evident that palliative care in primary health-care has been gradually developed, but it is necessary to consider the PH mode of organization and the social policies that su-

pport or weaken them, which is considered a complex challenge¹⁰.

Given the growing demand for PC, it is difficult to have a sufficient number of professionals to provide assistance. There are specialized centers, especially in large cities and hospital nuclei, but they do not communicate with the primary care network. In Brazil, rules have already been promulgated that establish PC and home care in the unified health system (UHS), to mention the most recent being the Better at Home Program. However, there are few places that work in this direction¹¹.

This perspective of healthcare does not only concern experts but can be provided by all healthcare professionals who are qualified through appropriate training^{7,12}. It is known that 80 to 90% of patients eligible for palliative care can be accompanied by family doctors and/or a family healthcare team¹³.

A central component of the good end-of-life practice is the properly timed identification of patients eligible for palliative care and their access to service¹⁴. Attention given shortly after the diagnosis of a life-threatening pathology increases the potential for pain relief and control of other symptoms, decreases psychological and family suffering, and reduces costs to the system¹⁵.

Considering the guiding principles of PC¹⁶, primary healthcare emerges as a place of potential identification of eligible patients. Family healthcare teams understand that longitudinality, their cultural and geographical proximity to users contributes to humanized care, respecting the autonomy of the patient and their families, and avoiding the fragmentation of the individual^{11,17}. Furthermore, the PHC may favor the care of the person at home, providing proximity to their family¹¹. Continuity of care in primary healthcare is valued by patients and is cost-effective for the health system by optimi-

zing resources^{3,7,18}.

Considering that chronic and life-threatening diseases make up the scope of a palliative care specialist's activities and the high capacity for early identification of these patients in PHC, the objective of this

work was to analyze data on the mortality that occurred in patients at the Vila Floresta Primary Healthcare Center within the Conceição Hospital Group (VFPHC-CHG) and verify how many of these would have been eligible for PC.

METHODOLOGY

This research is characterized by an observational, transversal, and descriptive study design with a retrospective quantitative approach. The context and focus where the study took place was the territory of the Vila Floresta Primary Healthcare Center of the Conceição Hospital Group located in the north of the Brazilian city of Porto Alegre. The VFPHC-CHG territory is characterized by the absence of large buildings, a population estimate around 16 thousand inhabitants, with its streets aligned with many trees and with irregular basalt stone pavement. The Conceição Hospital Group (GHC) is a public health institution and is formed by the Conceição, Child Conceição, Christ the Redeemer, and Feminine hospitals, as well as the Moacyr Scliar PHC, from 12 Community Health Service Stations, of which VFPHC-CHG is part of, three psychosocial care centers (PSCC) and the GHC school.

The sample, collected by convenience, are of people who belonged to the acting territory that died from January to December 2019. The information was compiled using the data files in a tabular format with a .csv extension and *RStudio* software (Version 4.2.1) for numerical analysis and descriptions. The data used comes from the CHG Electronic Registration System of the VFPHC-CHG Management Monitoring System, VFPHC-CHG patients' medical records, and Porto Alegre Epidemiological Surveillance data.

From the analysis those under the age of 18 and bearers of chronic non-communicable diseases who had sudden or violent deaths were excluded.

The data selected for mortality analysis were gender, age, the basic cause of death described by the main code of the International Classification of Diseases (ICD-10), associated comorbidities, addictions (alcoholism and smoking), diagnostic time of baseline disease, death date, passing place, professional who accompanied the end-of-life, and eligibility for PC. Age was categorized into three groups being young people (less than 59 years old), middle-aged (between 60 and 79), and the elderly (over 80). The time between diagnosis and death is calculated by the difference between the date of death and the date of the diagnosis of the disease that led to death and is divided into three categories, that is, in less than 6 months, or 6 months to 5 years, or more than 5 years.

Regarding the definition of eligibility for the need for palliative care, the *Palliative Care Screening Tool* (PCST) is shown in Figure 1. The scale evaluates four criteria: baseline disease, associated diseases, functional patient condition, and personal conditions of patient. When the score (sum of the four criteria) is greater than or equal to four points, they are considered eligible for palliative care.

Figure 1 – *Palliative Care Screening Tool (PCST)*

Criteria Number 1 - Baseline Diseases - Two points for each sub-item

1. Cancer-metastasis or recurrence
2. Advanced Chronic Obstructive Pulmonary Disease COPD - Repeated Exacerbations
3. Sequelae of cerebrovascular accident (CVA) - stroke – decreased motor function greater than or equal 25%
4. Severe renal insufficiency - Clearance of creatinine <25%, myocardopathy or significant coronary insufficiency.
6. Other diseases limiting the patient's life

Criteria Number 2 - Associated Diseases - One point for each sub-item

1. Liver Disease
2. Moderate kidney disease - Clearance of Creatinine <60ml/min.
3. Moderate COPD - Stable Clinical Picture
4. Moderate Congestive Heart Disease (CHD) - Stable Clinical Picture
5. Other associated diseases - The set is worth 1 point

Criteria Number 3 – Patient's Functional Condition

1. Patient's Functional Condition - This criterion evaluates the patient's degree of deficiency, taking into account the ability to perform usual daily activities, personal care acts, and the number of hours confined to the bed or wheelchair.

Score between 0 (patient is fully independent, active, which has no restrictions) and 4 (completely dependent, requires full-time help, confined to bed or wheelchair).

Criteria Number 4 – Patient's Personal Conditions - One point for each sub-item

1. Needing help for complex treatment decisions and undefined psychological or spiritual issues.
2. History of recent hospitalizations in emergency services.
3. Frequent hospitalizations for decompensation of the baseline disease
4. Extended Intensive Care Unit (ICU) hospitalizations or Patients already admitted to ICU with poor prognosis

Source: Adapted from Clara MGS, Silva VR, Alves R, Coelho MCR, 2019.³

For qualitative variables, we calculate the simple absolute and relative frequencies. The representation of the data was through univariate and bivariate tables. The study was developed after approval by the Research

Ethics Committee of the Conceição Hospital Group (REC/CHG), under the Certificate of Presentation for Ethical Appreciation (CAAE) No. 44618821.5.0000.5530 and Opinion Number 4.635.485 of 07/04/2021.

RESULTS

155 patients residing in the area covered by the Vila Floresta Healthcare Center (HC) who died in the period of 2019 were evaluated. Of the 155, 55.2% (n = 86) were female, 54.2% (n

= 84) were elderly over 80 years old, 80% (n = 108) died in hospitals, 34.8% (n = 54) were due to malignant neoplasms, and 42.6% (n = 66) were eligible for palliative care according to PCST.

Table 1 – Distribution of data frequencies of the mortality profile of residents in the territory of the Vila Floresta Primary Healthcare Center of the Conceição Hospital Group (n = 155). Porto Alegre, 2019.

Characteristics	Frequencies	
	Absolute (n)	Relative (%)
Sex		
Female	86	55.2
Male	69	44.8
Age (years)		
Young (Less than 59)	11	7.1
Middle-aged (Between 60 and 79)	60	38.7
Elderly (Above 80)	84	54.2
Time between diagnosis and death		
Less than 6 months	16	10.3
From 6 months to 5 years	17	11.0
More than 5 years	37	23.9
No information	85	54.8
Place of death		
Residence	27	17.4
Hospital	108	69.7
No information	20	12.9
Medical record at VFPHC-CHG		
Yes	52	33.5
No	103	66.5
Smoking		
Yes	13	8.4
Ex-user	14	9.0
No	13	8.4
No information	115	74.2
Alcoholism		
Yes	4	2.6
Ex-user	3	1.9
No	19	12.2
No information	129	83.2
Basic causes of death		
Neoplasms (C00 - D48)	54	34.8
Circulatory device diseases (I00 - I99)	29	18.7
Endocrinometabolic Diseases (E00 - E90)	15	9.7
Respiratory tract diseases (J00 - J99)	15	9.7
Nervous System Diseases (G00 - G99)	14	9.0
Other causes	28	18.1
Eligible for Palliative Care (PCST)		
Yes	66	42.6
No	5	3.2
No information	84	54.2

In Table 1, the other causes category is distributed as 6.5% (n = 10) for abnormal signs and symptoms (R00-Y98), 3.2% (n = 5) for external causes injuries (S0-Y48), 2.6% (n = 4) for diseases of the urogenital tract (N00-n99), 1.9% (n = 3) for infectious diseases (A00-B99), 1.9% (n = 3) for Digestive Diseases (K00-K93), 1.3% (n = 2) for osteomuscular disease (M00-M99), and 0.6% (n = 1) for mental health problems (F00-F99)

Table 2 – Distribution of absolute and relative bivariate frequencies of relationships between basic causes of deaths, place of death, and medical records at VFPHC-CHG. Porto Alegre, 2019.

Basic causes of deaths	Medical record at VFPHC-CHG	Place of death	
		Hospital	Residence
Neoplasms	Yes	18 (11.6%)	17 (12.6%)
	No	36 (23.2%)	29 (21.5%)
Circulatory Diseases	Yes	10 (6.5%)	5 (3.7%)
	No	19 (12.3%)	12 (8.9%)
Endocrino-metabolic Diseases	Yes	7 (4.5%)	4 (3.0%)
	No	8 (5.2%)	4 (3.0%)
Diseases of the respiratory tract	Yes	5 (3.2%)	5 (3.7%)
	No	10 (6.5%)	8 (5.9%)
Nervous system diseases	Yes	3 (1.9%)	2 (1.5%)
	No	11 (7.1%)	5 (3.7%)
Other causes	Yes	9 (5.8%)	4 (3.0%)
	No	19 (12.3%)	13 (9.6%)

In Table 2, it is observed that the minority (33.5%; n = 52) of people who died did not have medical records at VFPHC-CHG, 11.6% (n = 18) died of neoplasms, 6.5% (n = 10) by circulatory disease, 4.5% (n = 7) due to endocrine-metabolic diseases, and 3.2% (n = 5) due to respiratory tract diseases. On the other hand, the majority 69.7% (n = 108) died at the hospital, 12.6% (n = 17) had and 21.5% (n = 29) did not have medical records at VFPHC-CHG and died of neoplasms, 3.7% (n = 5) had and 8.9% (n = 12) did not have medical records at VFPHC-CHG and died of circulatory diseases.

Table 3 – Distribution of absolute and relative bivariate frequencies of relationships between gender, age and time between diagnosis and death in the VFPHC-CHG coverage area. Porto Alegre, 2019.

Sex	Age	Time between diagnosis and death		
		Less than 6 months	From 6 months to 5 years	More than 5 years
Female	Young	0 (0.0%)	0 (0.0%)	1 (1.4%)
	Middle-age	5 (7.1%)	8 (11.4%)	5 (7.1%)
	Elderly	4 (5.7%)	2 (2.9%)	14 (20.0%)
Male	Young	0 (0.0%)	1 (1.4%)	0 (0.0%)
	Middle-age	6 (8.6%)	5 (7.1%)	6 (8.6%)
	Elderly	1 (1.4%)	1 (1.4%)	11 (15.7%)

In Table 3, elderly with over 5 years between diagnosis and death are the most frequent in both sexes, females at 20% (n = 14) and males at 15.7% (n = 11). Another observation is concerning middle-aged

women from 6 months to 5 years of time between diagnosis and death was 11.4% (n = 8), followed by middle-aged men with less than 6 months between diagnosis and death 8.6% (n = 6).

DISCUSSION

The present study identified that 42.6% (n = 66) of people who died and lived in the territory of VFPHC-CHG demonstrated eligibility criteria for palliative care after filling out the PCST scale, and that only 33.5% (n = 52) had medical records at VFPHC-CHG. Incomplete and/or inadequate reports in the medical records also constituted a limiting aspect for accurate attribution of PCST scale points. Part of the medical records did not have sufficient information to apply the PCST scale, including fragility of basic information, such as comorbidities and addictions. It is noteworthy that 66.5% (n = 103) of the deaths that occurred that year had no medical record at the VFPHC-CHG. The completion of the PCST scale according to the data available in medical records was only possible for 45.4% (n = 71) patients. Of this set, 92.9% (n = 66) received a score in the analysis of the medical record for eligibility for palliative care.

On the other hand, at 69.7% (n = 108) the place of death was recorded at the hospital, this data is quite relevant when we consider the need to internalize the importance of work together as a general healthcare team and early enough with the specialized teams in palliative care for patients with life-threatening diseases¹⁹ and, urgently, the inclusion of PC training and preparation in PHC. It was observed that from the patients eligible for palliative care and who died in a hospital environment, few were assisted by a specialized team. This may reveal that there is a technical ignorance about when to activate PC teams or even ignorance of

how the healthcare system is organized. We recognize that the better integration of the healthcare services network, the better patient's care will be. The transverse actions and healthcare services should occur through communication and records between all points of the network.

According to the literature, there are general markers that are associated with a worse prognosis and, therefore, the need for specific evaluation for indicating PC: Advanced Age, Multiple Comorbidity Association, reports of the family concerning greater dependence on third parties for accomplishment of the basic activities of daily life, significant worsening of food intake, and recurring infections and/or difficult treatment, alcoholism, and smoking⁷.

It is important to highlight that the scales, including PCST, do not take into account only the diseases that the person has. Functionality, history of hospitalizations, and even decision-making capacity are other similarly important criteria that are usually better known by continuing care teams, reinforcing the PHC's ability to be part of and improve care at the end of life³.

The study presents limitations regarding the generalization of results for contexts with distinct population characteristics. Another limitation consists of the absence of data concerning the time between diagnosis and death among 54.8% (n = 85), the death site for 12.9% (n = 20), smoking for 74.2% (n = 115), alcoholism for 83.2% (n = 129), and palliative care eligibility for 54.2% (n = 84). Of the patients analyzed

in this study, 8.4% (n = 13) were active smokers and 9% (n = 14) were ex-smokers which represent 67.5% of the valid cases. In studies that address chronic obstructive pulmonary disease (COPD), this was the fifth major cause of reported death, and smoking was related to almost every other cause. Risk stratification in COPD and mortality shows that predictive scores can be simple, incorporate important clinical variables into specific comorbidities, significantly improve the predictability of problems, and improve performance of therapeutic activities²⁰.

Regarding the time between diagnosis and death, excluding the 85 cases without information, it was found that 52.8% (n = 37) had a time exceeding 5 years, which shows that most of these patients did not have their PC activated by the PHC in time to organize a care plan. One justification would be for the patient to be accompanied by other services, especially a hospital. In contrast, there was no communication between the secondary and tertiary networks with the primary network for joint management of the therapeutic project.

An anticipatory care plan increases the chance of identifying PC-eligible patients and their support core, starting this timely care, which positively affects posterior outcomes, strengthens the patient and family's autonomy, and corroborates shared decision-making, while avoiding invasive measures that would not change the course of the disease and increasing the number of assisted deaths in community services or even at home^{13,14}. Analyzing the publication of Brownlee *et al.*, the excessive use of aggressive measures at the end-of life is short of what would be ideal for palliative care at this stage²¹. It is noteworthy that the artificial extension of life refers to the contraindication of cardiovascular resuscitation, orotracheal intubation, and ICU referral (in the case of patients allocated

in hospital wards).

Among all the care analyzed, only those linked to a palliative care service had professional meetings and family reception records. The terminality process was addressed by other specialties near the date of death or only if comfort measures were enlisted. Family reception aimed at the person-centered approach makes room for the patient and family to share decision-making, aligning expectations, assisting care, and welcoming those involved²².

The discussion of the place of death is a matter pertinent to the end of life. Dying at home is the preferred place of most of the world's population, and of the Brazilian population (65%)^{3,7,9,23}. However, half or more die in hospitals (with large regional variations)^{7,8,24}. In this study, of 135 patients evaluated, 80% (n = 108) died in the hospital. Of the 27 patients who died at home, less than half (n = 12) were tied with the healthcare center.

It is important to emphasize the growing incentive of Brazilian public health policies regarding home care. Both home management of chronic non-communicable diseases and palliative care precepts are well defined and structured in theory by the Ministry of Health ordinances. The three modalities of home care (AD1, AD2, and AD3) cover PC in their various complexities²⁵. PHC fits the AD1 modality and if well managed is capable of remedying most of the demands of palliative patients efficiently concerning the treatment of symptoms such as pain, anxiety, depression, and weakness²⁶.

Among the patients with PCST scores of greater than or equal to 4 with descriptions in medical records that they were not assisted by the hospital palliative care team, there is no record on the preference of the patient and family members regarding the place of death. Among the gaps in patient

care among care levels, not discussing possibilities of the place of death and user preference to occur at home is one of them^{25,26}.

Home visits and the involvement of family and community doctors (FCD) improve the quality of care by knowing the reality of the patient and family dynamics. To welcome and enable the family and caregiver, prevent, treat, or respond more quickly to clinical demands brings benefits to both the patient and the optimization of the use of the healthcare services network. Home visits by FCD to patients in a terminal state of cancer in a population of Canada decreased by 15% the number of hospitalizations in general hospitals²³. In addition, the quality of care and the place where it is performed also becomes significant for the mourning process experienced during the illness and after the patient's death^{7,27}.

The skills-based curriculum is a strategy for inserting PC during medical education. The pillars of this proposal are to know

the precepts and principles of the PC, to understand the aging process and the epidemiological-demographic transition in Brazil, to properly handle the diagnosis and treatment of the most prevalent chronic diseases, and to provide verification of death¹⁹.

From the results of this study, it was realized that the basic skills necessary for FCD on the subject need to be developed through training and teaching strategies that prioritize practices, since there is the demand for this type of assistance by the population. This material is expected to be a subsidy for reflections inherent to the theme and to foster expanded discussions about the need for PHC qualification and better user service. A PHC that is capable of putting into practice its theoretical principles can create an ideal interface with secondary and tertiary levels and, thus, builds better care dynamically and in stride with progressive improvements at all ends of the healthcare system.

CONCLUSION

This study sought to analyze data on the mortality that occurred in VFPHC-CHG patients and verify how many of these would be eligible for PC. The results reflect the need to perfect the policies of healthcare in the care network regarding the scarcity of active search, systematized tools for care practice, team training, lack of physical resources, and lack of references of hospital services with PC teams.

The organization of protocols for the application of scales and identification of patients with eligibility criteria, planning and coordination of multiprofessional care, as well as the reception of the family together are necessary measures for effective

implementation of these precautions in PH.

Strengthening in PH reduces complications attributed to long hospitalizations, early discharge, reduction of public spending, and especially a quality of life for the patient. The organization of public health policies aimed at access, organization of qualified human resources, and well-established programmatic actions, with technical and human multiprofessional training, are fundamental elements for a cohesive end-of-life healthcare network and committed to ethics and the dignity of a human person.

It is concluded that the profile of people with diagnosis for more than five years of the disease that resulted in death could have

been observed more carefully by primary territory, and seeking to establish more healthcare teams regarding palliative care, effective communication with hospitals, thus increasing active searches in the especially in the transfer of care.

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