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Original Articles

Prospects for palliative care in primary healthcare: a descriptive study

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ABSTRACT

Aim: To identify eligible patients for palliative care and characterize the services involved in primary healthcare. **Method:** This was a descriptive and documental study conducted in 19 health units in a municipality in the countryside of Minas Gerais in Brazil. The Karnofsky performance scale was applied to the medical records of patients in the health sector with the largest number of eligible individuals. **Results:** We identified 2,715 eligible individuals, representing 3.59% of the registered population and 25.3% of patients in sector seven, which had the highest number of eligible individuals. Diabetes was the most common pathology, followed by cancer and cardiovascular diseases. Furthermore, 17.2% of these individuals have required palliative care precociously; 9.7%, required exclusive care, and the elderly above 60 years constituted the highest number among those eligible. **Discussion:** The data confirmed the need for structuring the primary healthcare for early care in palliative care, especially for the elderly. **Conclusion:** It is necessary to structure a care network that is integrated and ordained by PHC and professional training.

Descriptors: Palliative Care; Primary Health Care; Karnofsky Performance Status.

INTRODUCTION

Brazil faces a period of demographic and, consequently, epidemiological transition in its population. There is a clear reversal of the age pyramid in the country: the elderly population has increased considerably compared to the number of children in Brazil, leading to increased prevalence of chronic non-communicable diseases (NCD)[1] and an increase in discussions about the need for health models to prioritize palliative care (PC)[2].

PC refers to the assistance provided by health professionals and volunteers to individuals with chronic diseases that threaten their life and they offer biopsychosocial and spiritual support to patients and their families[3]. The goal of PC is to provide quality care and reduce hospital admissions and unnecessary assistance. However, the achievement of this goal requires better integration of health services using a person-centered and decentralized approach[2].

In this context, primary healthcare (PHC) should operate as the gateway and the center for communicating with the *Rede de Atenção à Saúde* (RAS, the Healthcare Network), since it is decentralized and values the proximity of the services with the population. The services provided are considered to be highly complex and of low technological density, and actions are organized through a multidisciplinary team. PHC is provided by Primary Healthcare Units (PHCU), while the Family Health Strategy (FHS) is the form of action used in the Brazilian context[4].

Many patients die before receiving PC and it is therefore important to make sure that care is available as much as possible for both patients and within PHC. In Europe, some studies have already addressed this issue and have recognized the importance of implementing national education policies for the population and ensuring the provision of medicine in PHCUs[2-3,5].

Although there is evidence of the positive impact of early PC, this type of care has been provided to patients who are in the advanced stages of illness. In the Brazilian context, there is no reliable information on how and when patients are referred to the PC; however, it is believed that they receive PC in the later stages of their illness[6].

The aim of this study was to identify patients eligible for PC and to characterize the services involved in PHC. In addition, the study also proposed to analyze the challenges PC in the Brazilian context by focusing on the structure of the RAS.

METHOD

This was a descriptive and documental study. Descriptive studies are designed to determine the distribution of diseases or health-related conditions according to the time, place and/or the characteristics of individuals[7]. Data were collected from December 2014 to March 2015. The application of the method was guided by the following questions: how is the attention given to PC organized in the PHC municipality? What is the population that demands this type of care? What are the characteristics of this population and of these PHC services? What are the challenges in PC in PHC?

It is worth noting that, before starting the study, it was necessary to understand the organization of PHC in the municipality. Thus, by means of a map made available by the health department, the researchers identified that the municipality is divided into 12 sectors or health regions and that each sector contains a

PHCU. Some units are based on the FHS model and others are based on the traditional Basic Health Units (BHU) model.

After this identification, the researchers decided to conduct the survey in seven sectors of the city, since the PHC of the FHS model is in these sectors, thus allowing a more comprehensive understanding of the actual population served.

The study was conducted in two stages. In the first stage an initial survey of patients eligible for PC in the seven health sectors was conducted. Thus, a total of 19 PHCUs, with 75,524 registered individuals, was identified in the seven sectors. To conduct the survey on the number of individuals eligible for PC, the researchers used an instrument they had developed and the survey was completed by nurses and community health workers (CHWs) who work within the 19 PHCUs.

The instrument used featured a picture in a two-column format. In the first column, the following conditions/diseases were presented: Alzheimer's disease (AD) and other dementias; cancer; cardiovascular disease (except in cases of sudden death); liver cirrhosis; congenital anomalies; meningitis sequelae; hematologic and immunological diseases; neonatal conditions; chronic obstructive pulmonary disease (COPD); diabetes; acquired immunodeficiency syndrome (AIDS) or human immunodeficiency virus (HIV); chronic renal insufficiency (CRI); multiple sclerosis (MS); Parkinson's disease; rheumatoid arthritis; and resistant tuberculosis. Such conditions were listed according to the criteria of the World Health Organization (WHO) in order to indicate which patients were eligible for PC[3]. In the second column there was a blank space so that nurses or the CHWs could indicate the number of patients who presented each condition/disease in their PHC.

After identifying the demand for eligible patients (2,715; 3.59%) and discovering that, among the seven sectors, sector seven had the highest number (687; 25.3%), the *Karnofsky* performance scale (KPS) was applied, along with the medical records of patients in that sector, in order to characterize and classify patients in terms of their need to receive early and exclusive PC. It should be noted that, at the time of the study, the six PHCUs in this sector had, all together, an estimated 19,555 people registered.

The KPS is used to measure the functional capacity of people suffering from any disease and may also assist in the prognosis formulation of patients with chronic disease. Its use is free and payment is not required. Patients with performance values below 70% show an early indication of a need for PC assistance, while a performance of 50% or less indicates exclusive or end-of-life care, reaffirming that these patients are eligible for exclusive PC[8]. For the application, the medical records of eligible patients were used because these are documents in which health professionals make clinical follow up. Thus, the records contained within patients' medical charts enabled the adoption of KPS.

The research project was previously submitted for assessment by the Ethics Committee for Research with Human Beings at the proposing institution and the study received approval number 742,851.

RESULTS

In the first stage of the research, it was possible to identify the number of patients eligible for PC in the seven sectors surveyed. This number totaled 2,715 patients. Considering the initial population of 75,524 individuals, this

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number represents 3.59% of the registered population. The data collected in the initial stage of the study are shown in the following table.

Table 1 - Number of patients eligible for palliative care in the Family Health Strategy of the municipality of Minas Gerais, Brazil, 2015.

Sanitary Sector	Total Eligible (n)	%
5	229	8,4%
6	495	18,2%
7	687	25,3%
8	356	13,1%
9	366	13,5%
11	360	13,2%
12	222	8,1%
TOTAL	2.715	100%

As shown in Table 1, the sector with the largest number of patients eligible for PC, according to WHO criteria, was sector seven (n=687/25.3%).

In relation to the second stage results, Table 2 identifies the distribution of the number of patients according to conditions/diseases by age group.

It was noted that diabetes (n=499/72.6%) was the pathology that most affects patients, followed by cancer (n=30/4.4%). As for the patients with two diagnostics, the pathology that occurred most frequently (n=19/33.3%) was diabetes with cardiovascular disease. It was also noted that the largest group of patients was those aged 50-59 years (n=188/27.4%), followed by patients aged 60-69 years (n=182/26.5%).

As for the number of patients diagnosed in the disease groups described in Table 2, there was a predominance of certain pathologies in each group. The cardiovascular diseases group included stroke sequelae (AVE) (n=23/52.3%) and congestive heart failure (CHF) (n=14/31.8%). Among the cases of neoplasia there was a predominance of breast cancer (n=11/31.4%) and prostate cancer (n=7/20.0%). Among the congenital anomalies, there were more cases of Down syndrome (n=5/45.4%). Also, for cases of hematological and immunological diseases, lupus was predominant (n=4/44.4%). Lastly, in relation to neonatal conditions, the most frequent condition was cerebral palsy (n=6/54 5%).

Table 2 - Distribution of users in the sector seven, according to age and conditions/diseases (n=687), Minas Gerais, Brazil, 2015.

Pathology	0 a 19		20 a 49		50 a 59		60 a 69		70 ou +		TOTAL	
	n	%	n	%	n	%	n	%	n	%	n	%
Alzheimer and dementias	-	-	-	-	-	-	3	0,4	10	1,4	13	1,8
Cancer	1	0,1	7	1	7	1	4	0,6	11	1,4	30	4,7
Cardiovascular disease	-	-	1	0,1	7	1	14	2	5	0,7	27	3,9
Parkinson	-	-	1	0,1	1	0,1	1	0,1	1	0,1	4	0,4
Hepatical cirrhosis	-	-	1	0,1	-	-	2	0,3	-	-	3	0,4
Congenital anomaly	5	0,7	2	0,3	-	-	-	-	-	-	7	1
Sequel of meningitis	-	-	-	-	-	-	-	-	1	0,1	1	0,1
hematologic and immuno d.	-	-	5	0,7	-	-	1	0,1	-	-	6	0,8
Neonatal conditions	4	0,5	5	0,7	-	-	1	0,1	-	-	10	1,3
COPD	-	-	-	-	2	0,3	2	0,3	4	0,6	8	1,2
Diabetes	9	1,3	94	13,7	158	23	137	19,9	101	14,7	499	72,6
HIV	-	-	1	0,1	-	-	1	0,1	-	-	2	0,2
CRF	-	-	3	0,4	1	0,1	-	-	3	0,4	7	0,9
Rheumatoid arthritis	1	0,1	4	0,6	4	0,6	2	0,3	1	0,1	12	1,7
Resistant tuberculosis	-	-	-	-	-	-	1	0,1	-	-	1	0,1
Several diagnoses	1	0,1	8	1,2	7	1	13	1,9	28	4	57	8,3
TOTAL	21	2,8	132	19	188	27	182	27	164	24	687	100

In the second stage of the study, KPS was applied to the records in order to perform classification concerning the need for early or exclusive PC. Table 3 shows the distribution of patients according to the healthcare facility and the value of KPS.

Regarding the distribution of patients in terms of PHC and KPS value, it was clear that in relation to the number of patients eligible for early PC, the unit with the largest number of patients (n=29/24.6%) was PHCU 7. In relation to exclusive PC, the unit with the largest number of patients (n=19/28.3%) was PHCU 8.

In terms of the results from the second stage of the research and the data relating to KPS value by age group, it was noted that most of the patients (n=276/86.5%) aged between 20 and 59 years presented KPS above 80%, thus indicating complete functional independence. On the other hand, the age group that included the highest number of patients classed as eligible for early PC—that is, individuals with a performance score below 70%—were patients aged 70 years or older (n=55/46.6%). The age group with the greatest number of patients eligible for exclusive PC was also patients who were 70 years or older, with 28 (41.8%) patients.

As for the sex of the patients, 416 (60.5%) were female and 271 (39.5%) were male. Also,

in relation to pathology according to the sex of the patients, it was noted that most of the diseases affected men and women equally. However, in terms of the diabetic patients, it was perceived that a larger number were women (n=300/60.1%).

As for the characterization of the PHCU that make up sector seven, all have a health team that includes: a nurse; a nursing technician; a doctor; a dentist; an oral health technician; and CHWs. Moreover, a resident in nursing and a single professional physiotherapist who were responsible for servicing this sector were also part of the team for two units. Thus, the total number of professionals who were working in the units in this sector was eight nurses, six nursing technicians, two nursing home residents, six dentists and six oral health technicians, eight doctors (of which three take part in the More Doctors Program), a physiotherapist and 20 CHWs.

In terms of the population assisted in this sector, three PHCU cover the countryside in their area, while the others cover urban areas only. In relation to the physical space of these units, all units work in adapted houses so that they are easily accessible for the population using municipal public transport. The units operate from 7am to 5pm, five days a week. These opening hours may limit patient access

Table 3 - Distribution of patients by health units in the sector seven and value of KPS *, Minas Gerais, Brazil, 2015.

PHCU	KPS Value*									
	20 to 30		40 to 50		60 to 70		80 or +		TOTAL	
	n	%	n	%	n	%	n	%	n	%
PHCU 5	3	0,4	9	1,3	11	1,6	83	12,1	106	15,4
PHCU 6	-	-	13	1,9	18	2,6	124	18	155	22,6
PHCU 7	-	-	8	1,2	29	4,2	60	8,7	97	14,1
PHCU 8	1	0,1	18	2,6	21	3,1	73	10,6	113	16,4
PHCU 9	-	-	7	1	19	2,8	67	9,8	93	13,5
PHCU 10	-	-	8	1,2	20	2,9	95	13,8	125	18,2
TOTAL	4	0,6	63	9,2	118	17	502	73,1	687	100

Karnofsky Performance Scale.

to PC, as the units are closed over the weekends and during holidays; therefore, some long-term care stops during these times. In this case, when patients need care, they should seek assistance from their municipality's *Unidade de Pronto Atendimento* (UPA, Emergency Care Unit).

In terms of the reference and counter-reference system for the secondary level, there is a central polyclinic that provides specialties such as cardiology, gynecology, endocrinology, neurology, general surgery and psychiatry, as well as care related to the Specialized Care Service (SCS) and hearing healthcare and diagnostic support. All these services are performed by means of medical forwarding to the PHCU. In many cases, patients report a long waiting period between scheduling an appointment and clinical evaluation. It is important to note that, particularly for patients diagnosed with cancer, patients are, in large part, referred to a large hospital that is specialized in cancer treatment in the region state of the Midwest, located in the city researched in this study.

Concerning the assistance provided by PC, it was noted that the materials offered to patients are basically gauze, serum and tape—that is, material for bandages. There is also no care agenda for this type of care. Furthermore, pain medication is not distributed by the PHCUs to the registered population since it is distributed by the BHUs and the central pharmacy. It was also identified that nurses who participated in the study did not have specific training in PC and had never participated in training on the subject.

DISCUSSION

The results of this study showed a small percentage (3.59%) of patients eligible for

PC in PHC. However, it is believed that such rates may be related to a lack of evaluation and monitoring of this type of patient in PHC.

The results also point to a problem that is still frequent in Brazilian municipalities: the lack of FHS coverage. In this study, it was found that only seven of the 12 health sectors of the city are covered by the FHS.

In terms of the application of KPS, it was observed that, of the total number of patients eligible for PC, only 17.2% required early PC, while only 9.8% required exclusive PC. This number is a result of the fact that most of those eligible for PC presented diabetes as the main diagnosis, a condition that receives special attention through the implementation of policies that advocate for the improvement of diagnosis and treatment within PHC[9].

It is noteworthy that there have been no studies that have applied KPS to patients in PHC; however, a study with the objective of using KPS to evaluate the functional capacity of patients who were 70 years or older and who had undergone brain tumor removal found that a total of 90 patients showed more than 70% presented KPS greater than 80%[10]. In this study, 50% of patients aged over 70 showed a KPS value greater than 80%.

In terms of the need for early PC, it is known that the elderly are the group most likely to receive this kind of PC, especially when subjected to long therapies for chronic diseases, such as dementia, cancer, heart disease, lung disease and nephropathy[11]. This study found that people aged over 70 were the most suitable (83/44.9%) to receive early or exclusive PC, followed by people aged between 60 and 69 (50/27.0%).

The results from the second stage indicated patients' average age as 58 years old; however, there were patients identified who were aged between one and 101 years. Re-

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cent data has estimated that, every year, over 20 million people around the world require end-of-life PC and that 69% of these people are elderly (aged 60 and over), while 25% of people aged between 15 and 59 years and 6% of children require end-of-life PC[3]. Although, the majority of patients who receive PC are elderly, it is clear that this type of care is offered to individuals of any age.

In terms of diabetes, the most common pathology found in the eligible individuals included in this study, the average prevalence around the world is around 10% of the population. In Brazil, it is estimated that there are 12,054,824 diabetic patients in the country[12]. These statistics reveal the magnitude of this disease in the present moment and the need for early care aimed at preventing complications.

It important to emphasize the predominance of diabetes in the women included in this study. Although another study[13] also achieved a similar result, it is believed that, in this case, one should take into account the fact that approximately 60% of the survey participants were women. Moreover, it is important to note that the studies that we analyzed referred only to cases of diabetes mellitus, while in this investigation it was not possible to classify the patients according to their type of diabetes, since this information was not always available in the medical records.

We should also emphasize the fact that, in this study, among the patients who had more than one diagnosis that is recommended by WHO as eligible for PC[3], there was a predominance in terms of the relationship between diabetes and cardiovascular disease, which was experienced by 19 (33.3%) patients. It is known that cardiovascular diseases are the leading causes of death in people with diabetes. A cohort study involving 49,582 people in Finland found that hypertension and diabetes were independently associated with an increased risk of incidence and mortality from strokes[14]. Therefore, attention should be paid to the relationship, considering that complications, such as strokes, are related to the prescription of exclusive PC.

After diabetes, cancer was the second pathology that affected the most patients in the study. In Brazil, it has been estimated that 2015 saw approximately 576,000 new cases of cancer, thus increasing the magnitude of the country's cancer problem[15]. Therefore, it is important that PC is viewed as an extremely necessary measure in promoting quality of life and in preventing and alleviating the suffering of individuals and their families.

Despite the occurrence of Alzheimer's disease and other dementias having been identified at a lower percentage in this study, it is known that the former is considered to be one of the more prevalent depressive and demential syndromes in individuals aged over 65[16]. Therefore, this data did not correlate with the results found in this study, suggesting the difficulties of diagnosing these diseases and the absence of records in the surveyed PHCUs.

Another finding that needs to be discussed is the fact that only two patients among those eligible for PC had a diagnosis of HIV. This finding is concerning because the vast majority of young adults who require end-of--life PC are affected by this disease[3]. The management of the care provided to HIV-positive patients that is shared between the primary and secondary networks is the key to improving care for HIV carriers in Brazil, since this allows early diagnosis and helps ensure early treatment in a timely manner[17]. The absence of any diagnosis in patients' medical records may be related to the secrecy surrounding the disease, which is stigmatized in the Brazilian

context. Thus, the results of this study show a considerable number of patients receiving PC in PHC and, in turn, the lack of organization and structure of services to meet this demand.

Currently, it is possible to see an inadequate configuration of care models in health services. These models are marked by inconsistencies between the provision of services and the health needs of the population; that is, the organization of care has not followed the downward trend of acute problems and the rise of chronic conditions. To overcome such deficiencies, it is necessary to rescue the RAS, whose aim is to promote the systematic integration of health actions and services with the provision of continuous, integral, quality, responsible and humane care, as well as to increase system performance in terms of access, equity, clinical and health effectiveness and economic efficiency[18].

As evidenced by Brazilian decree no. 4,279, which refers to the RAS[18], in the case of health facilities in the sector studied in this research, assistance is still based on the curative model, in which patients with a need for PC are often not seen as a priority by the teams that should conduct more frequent home visits. Another important fact in relation to the organization of PHC services in the municipality—mainly for patients receiving PC—concerns the difficulties in scheduling specialized care; that is, the articulation between the primary and secondary healthcare levels. When consulting the records at the second stage, it was identified that there were cases when patients had waited over a year to be seen by cardiology specialists, for example.

In this context, home care (HC) has developed as a new form of healthcare, the aim of which is the reorganization of the work processes of the teams that provide HC in PHC, clinics, emergency services and hospitals. One

of the objectives of this reorganization, among other goals, is to reduce the length of stay of admitted users[19].

HC has been adopted by Brazilian public policies as an alternative to hospitalization. In the *Sistema Único de Saúde* (SUS, Unified Health System), the care format was established by Law no. 10,424, of 15 April 2002, which defines this type of assistance, and by Decree no. 2,529, of 19 October 2006, which defines forms of action, care staff training, financial resources and credentialing conditions. More recently, some forms of HC have been redefined by Decree no. 963, of 27 May 2013, which established the Home Care Service (HCS) in the SUS, both defining the formation of the *Equipe Multiprofissional de Atenção Domiciliar* (EMAD, the Home Care Multidisciplinary Team) and making a provision for the inclusion of PC and assistance in death its prerogative[20].

Ordinance no. 963 also emphasizes the role of PHC in HC and it is described as home care type 1 (HC1), which serves the population that has controlled health problems and individuals with physical difficulties or those who are unable to travel to the unit, in addition to those who require less complex and less frequent care[19]. However, considering the Brazilian panorama of scarcity of services and specialized teams in PC, PHC starts to play an important role in the coordination of care.

However, for the implementation of HCS and EMAD in the SUS, some requirements have been imposed on municipalities. One of these requirements is to be covered by the *Serviço de Atendimento Móvel de Urgência* (SAMU, Mobile Emergency Service). Although the city's population meets the required number for the implementation of this type of assistance, this does not make up the local RAS in the city studied in this research. Therefore, when considering the care aimed at patients in PC,

it is believed that this fact deserves managers' attention, since HC ensures a reduction in demand for hospital care and, consequently, public expenditure, in addition to helping ensure patients have a freedom of choice as to the environment in which they want to spend the last days of their life[18].

CONCLUSION

Given that strong bonds between patients and their families are set out in the PHC, it is necessary that professionals are empowered to offer CP to people who require it, as the professionals working at this level of care know the needs of patients and may provide relief and comfort to such individuals.

It is necessary that each unit knows the levels of patient demand so they can make the necessary interventions. This study provides support for other municipalities to undertake this survey, since the adopted methodological approach used was effective in meeting such demands.

A limitation found was the lack of information provided in medical records. When this occurred, the CHWs were asked to better describe the health status of patients. Furthermore, nurses had difficulties regarding the survey of the number of eligible patients in the initial stage of the study. It is clear, therefore, that there are organizational and care problems in the units that help create an absence of records relating to the characteristics of the assisted population.

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