

# New demands for primary health care in Brazil: palliative care

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## New demands for primary health care in Brazil: palliative care

**Objective.** Assess the need for incorporation of palliative care in primary health care (PHC) through the characterization of users eligible for this type of care, enrolled in a program for devices dispensing. **Methods.** Descriptive study of case series conducted in 14 health units in São Paulo (Brazil) in 2012. It was included medical records of those enrolled in a program for users with urinary and fecal incontinence, and it was applied Karnofsky Performance Scale Index (KPS) to identify the indication of palliative care. **Results.** 141 of the

160 selected medical records had KPS information. Most cases (98.3%, 138/141) had performance below 70% and, therefore, patients were eligible for palliative care. The most frequent pathologies was related to chronic degenerative diseases (46.3%), followed by disorders related to quality of care during pregnancy and childbirth (24.38%). **Conclusion.** It is necessary to include palliative care in PHC in order to provide comprehensive, shared and humanized care to patients who need this.

**Key words:** Palliative Care. Primary Health Care. Karnofsky Performance Status.

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## Nuevas demandas para la atención primaria en salud en Brasil: los cuidados paliativos

**Objetivo.** Evaluar la necesidad de la incorporación de los cuidados paliativos en la Atención Primaria en Salud (APS), a partir de la caracterización de los usuarios elegibles para esta modalidad de cuidados, registrados en un programa de dispensación de insumos. **Métodos.** Investigación descriptiva del tipo series de casos realizada en 14 unidades de salud del municipio de São Paulo (Brasil) en 2012. Fueron incluidas las historias clínicas de los usuarios registrados en un programa de dispensación de insumos para las incontinencias urinaria y fecal, siendo aplicado el Índice de *Karnofsky* (KPS) para identificar la indicación de cuidados paliativos. **Resultados.** 141 de las 160 historias clínicas seleccionadas tenían información de KPS. La mayoría de los casos (98,3%, 138/141) tenían desempeño por debajo del 70%, por lo cual eran pacientes elegibles para cuidados paliativos. Las patologías con mayor frecuencia se relacionaban con cuadros crónicos y degenerativos (46,3%), seguidos por las patologías relacionadas con la calidad de la atención de la gestación y el parto (24,38%). **Conclusión.** Existe necesidad de incluir los cuidados paliativos en la APS, con el fin de brindar un cuidado integral, compartido y humanizado a los pacientes que lo requieren.

**Palabras clave:** Cuidados Paliativos. Atención Primaria de Salud. Estado de Ejecución de Karnofsky

## Introduction

The whole world is going through a demographic transition, with an increase in the number of elderly people and chronic noncommunicable diseases (CNCD)<sup>1-4</sup> such as cancer, diabetes and cardiovascular diseases, many of them in advanced stages. Because of the technological advances regarding the detection and treatment of these diseases, which once progressed rapidly and led to certain death, they now become chronic conditions, with an increasing number of symptoms and functional decline throughout the years.<sup>1</sup> These advances contributed to the increase of life expectancy, which creates a growing number of fragile people who suffer from several chronic health conditions.<sup>4</sup> It is estimated

## Novas demandas para a atenção primária à saúde no Brasil: os cuidados paliativos

**Objetivo.** Avaliar a necessidade de incorporação dos cuidados paliativos na atenção primária à saúde (APS) a partir da caracterização dos usuários elegíveis para este tipo de cuidados, registrados em um programa de dispensação de insumos. **Métodos.** Estudo descritivo do tipo série de casos, realizado em 14 unidades de saúde do município de São Paulo (Brasil), em 2012. Foram incluídos prontuários de inscritos em um programa de distribuição de insumos para usuários com incontinência urinária e fecal, sendo aplicada Escala de Performance de Karnofsky (KPS) para identificar a indicação de cuidados paliativos. **Resultados.** 141 dos 160 prontuários selecionados tinham informações de KPS. A maioria dos casos (98,3%, 138/141) teve desempenho abaixo de 70% e, portanto, eram pacientes elegíveis para cuidados paliativos. As patologias mais frequentes relacionavam-se a quadros crônico-degenerativos (46,3%), seguidas pelas patologias relacionadas com a qualidade da atenção à gestação e ao parto (24,38%). **Conclusão.** Há necessidade de se incluir cuidados paliativos na APS, a fim de prestar um cuidado integral, compartilhado e humanizado aos pacientes que necessitam deste.

**Palabras chave:** Cuidados Paliativos. Atención Primária à Saúde. Avaliação de Estado de Karnofsky.

that in Europe 4.8 million people die every year, and two million die from severe chronic diseases such as cancer. Thus, facing the increasing number of elderly people and people living with CNCD, the World Health Organization (WHO) and the European Union (EU) now recognize the importance of Palliative Care (PC) at the end of life for public health.<sup>2</sup>

In Brazil, PC are mainly offered in hospitals, since this type of care is part of the Primary Health Care (PHC). Despite the fact that this level of care has specific home care programs, data from 2010, divulged by the Informatics Department of the Unified Health System (DATASUS), show that the hospital is where most deaths occur, reaching up to 80% of the cases.<sup>5</sup> Initially, the PC were related

to care given to patients with cancer. However, there is now a strong movement for the inclusion of other chronic diseases such as, for example, Acquired Immune Deficiency Syndrome (AIDS), congestive heart failure and neurological diseases. This movement is happening because of the growing effort to include this type of care in PHC<sup>1</sup>. In this sense, many countries have discussed and implemented initiatives that include PC in PHC<sup>1,2</sup>, among them Canada, Spain<sup>5</sup> and, recently, Brazil.<sup>1</sup> However, despite current intense debates about including PC as a type of primary care, it is estimated that about 20 million people all over the world still die without having access to this type of care, which could minimize the suffering and pain of these patients and their families.<sup>3</sup>

Palliative cares started during the Middle Ages, and they were the main type of care offered by religious institutions until the 18th century. Os CP tiveram sua origem na Idade Média, sendo o principal tipo de cuidado oferecido pelas instituições hospitalares religiosas até o século XVIII. Recently, the concept introduced by Saunders regarding specialized care for patients outside therapeutic possibilities led to the creation of specialized units called hospices.<sup>6</sup> Still, the development and world expansion of PC as a multi-professional approach total, active and continuing care given to the patients and their families,<sup>1,3,7,8</sup> is very recent, beginning in 1967, with the foundation of St. Christopher's Hospice, in London.<sup>6</sup> Nowadays, PC are not a specific place to die, but a philosophy of care wherever the patient is, including their home.<sup>6</sup> One criterion for being eligible for PC is that the patient suffer from at least one of the following diseases or conditions: Alzheimer's and other types of dementia, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, congenital anomalies, meningitis, immune and hematological disorders, neonatal conditions, Chronic Obstructive Pulmonary Disease (COPD), diabetes, Human Immunodeficiency Virus Infection (HIV/AIDS), renal failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis and resistant tuberculosis.<sup>9</sup> One of the most accepted eligibility criterion refers to the patient's life expectancy; the United States' Medicare establishes a minimum of six-month life

expectancy for the patient to receive exclusive PC. In order to establish this prognosis and recommend the PC, the instrument "ability for everyday tasks" is used. From this concept, the recommendation for PC becomes necessary when the patient is incapable of performing such tasks as moving around, feeding, and shows to be incontinent.<sup>10</sup>

However, there is still difficulty in establishing these eligibility criteria and also in deciding on these "terminal" diagnoses. This difficulty has been causing the use of prolonged interventions instead of the use of treatments to lessen suffering. Another problem is the discontinuity of treatment when transitioning from curative to palliative care, which causes the patients and their families to abandon treatment and isolate themselves.<sup>3</sup> Faced with this challenge, studies that focus on the identification of eligibility criteria for PC become relevant, since they constitute a necessary modality of care for treating this new demand by the population. In the Brazilian context, the Program for Community Health Agents (PCHA) and the Family Health Strategy (FHS), widely known around the country, although they were not originally developed to work with PC, may be structured to incorporate this type of care. The argument is that the community agents, because they know their communities so well, would be important links between the patients and the rest of the PHC team, since they would find out about the existence of these patients and identify their needs and the needs of their families<sup>1</sup>. Thus, a discussion about the need to incorporate these cares in PHC becomes necessary, considering the benefits of this incorporation for the quality of life of the patients and their families and for the organization of the health system. We understand that this incorporation may help decrease the patients' abandonment of the treatment and their suffering since, due to the characteristics of this type of care, it can cause hospitals and the PHC to work better together<sup>1</sup>. This study had the goal of discussing the incorporation of palliative cares to primary health care from the characterization of the users eligible to this type of care who were enrolled in a program for devices dispensing.

## Methods

Case studies are used as exploratory steps in the research of phenomena which have not been investigated, but require further study, in a reduced number of cases, in order to identify observation categories or generate hypotheses for further studies.<sup>11</sup> The context of the study were 14 health units in the PHC of the Parelheiros region, which has over 80% of its territory covered by the Family Health Strategy (FHS), in São Paulo, Brazil. The study was conducted in that region because it was considered by the City Health Department (CHD) of the city as one of the areas with high need for health care that should be prioritized in the distribution of health services in the city. Data collection was conducted between June and July 2012, from records containing the list of registered users enrolled in the Program for Dispensing of Urinary/Fecal Incontinency Matter (PDUFIM) and records of the users registered in this Program in the healthcare facilities that were surveyed. The choice of users registered in the Program was intentional, because of the access to information and the characteristics of the studied group. That is, from this Program, the patients who could be recommended for palliative cares could be identified, because of the relationship between functional abilities and recommendation for this type of care. The PDUFIM treats people who are older than three years old and are placed on stage 4 or 5 of Functional Incapability for Everyday Life Activities, based on the Scale for the Evaluation of Functional Incapability of the Spanish Red Cross. This scale is classified as follows: stage 0: patient depends completely on oneself and walks normally; stage 1: performs everyday activities sufficiently, has some difficulties with complicated movements; stage 2: presents some difficulties in everyday activities, and needs support sometimes; walks with the aid of a cane or something similar; stage 3: presents severe difficulties in everyday activities and needs support for almost all of them; walks with difficulty and needs the help of at least one person; stage 4: cannot perform any everyday activity without help; walks with a lot of difficulty, with the help of at least two people; stage 5: immobilized in a bed or couch, needs

continued care.<sup>10</sup> It is important to highlight that in the city of São Paulo the assessment of the patient following this scale is a criterion for the recommendation of home palliative cares..

The data of the users selected from the charts were: sex, age, International Classification of Diseases (ICD) of the type of incontinence, ICD of the base disease, classification on the Scale for the Evaluation of Functional Incapability of the Spanish Red Cross, ICD of the current disease and observations. In order to identify the users registered on the PDUFIM who could be recommended for PC, the Karnofsky Performance Scale (KPS) was applied, based on the chart records of these users regarding complaints, signs and referred symptoms, and the ability for self-care and performance of everyday activities. The KPS was developed as a way of assessing patients' ability to perform ordinary tasks, based on the doctors' clinical observation. This scale is considered to be very useful for the assessment of patients receiving PC, although its use is not restricted to this public. The scale is divided as follows: 100% - normal, no complaints, no signs of disease; 90% - capable of performing ordinary activities, few signs or symptoms of disease; 80% - performs ordinary activities with some difficulty, has some signs and symptoms; 70% capable of caring for oneself, incapable of performing ordinary activities and working; 60% - needs some help, is capable of taking care of most personal needs; 50% frequently needs help and medical care; 40% - incapable, needs special care and help; 30% - severely incapable, should be admitted to a hospital but has no risk of death; 20% - very sick, needs immediate admission and support measures or treatment; 10% - dying, rapid progression towards a fatal disease; 0% - death.<sup>10</sup> The patients are divided into different groups in relation to the type of assistance they need for their personal care. We consider that patients with performances of under 70% in the KPS scale have early recommendation for PC, and a performance of 50% in this scale indicates low life expectancy, reaffirming that these patients are eligible for PC.<sup>10</sup>

Thus, the study was performed following these steps: 1 – Initial contact with the managers from the 15 health units of the area for planning the research activities. During this stage, one unit was excluded because the manager was on vacation. 2 – Data collection from the 180 records from patients enrolled in the PDUFIM. During this stage, only 160 patient records were found. 3 – Locating the charts of the patients enrolled in the Program for applying the KPS. In this stage, we applied the scale to 141 charts from 11 units. Two health units were excluded because they did not keep the necessary information for the data collection instrument. Data was analyzed through simple descriptive statistics and were presented in charts and tables, and in a descriptive manner. The study was approved by the Ethics Committee for Research of the Health Department of São

Paulo on May 8th, 2012, under register nº 071/12. All participants (users of the PDUFIM) signed a Clarified Consent Term (CCT), and they were all told why their data was being collected.

## Results

From the 14 Basic Health Units (BHU) selected for this study, data could not be collected in only one because the manager was on vacation. This exclusion happened during the first stage of the research when the managers from the selected units were being contacted. In the 13 remaining units, there were 180 (100%) users enrolled in the PDUFIM, as shown in Table 1. However, only 160 (88.8%) registers from these users were found for data collection.

**Table 1.** Distribution of the number of users enrolled in the PDUFIM (n=180), according to location, name of the health unit and enrolled population.

Health Unit	Enrolled population	Nº of users	% of users
Urban area			
Iporã	14 243	40	22.22
Vargem Grande	17 526	32	17.78
Recanto	17 526	23	12.78
Vila Roschel	5 849	14	7.78
Silveira	3 433	9	5.00
Colônia	4 848	8	4.44
Vila Marcelo	5 281	7	3.89
<b>Sub-total</b>	<b>68 706</b>	<b>133</b>	<b>73.89</b>
Rural area			
Fontes	6 525	15	8.33
Barragem	5 210	12	6.67
Marsilac	2 000	6	3.33
Embura	5 419	6	3.33
Dom Luciano	1 734	6	3.33
Nova Améria	3 725	2	1.11
<b>Sub-total</b>	<b>24 613</b>	<b>47</b>	<b>26.11</b>
<b>Total</b>	<b>93 319</b>	<b>180</b>	<b>100.00</b>

The minimum and maximum age of the users enrolled in the PDUFIM varied from 4 to 98 years old, and the average age was 46.6 years old, with standard deviation of 29.8 years, which shows a prevalence of young adults in the analyzed

population. Regarding sex, 78 participants were male (48.75%) and 82 were female (51.25%). In the age group from 15 to 49 years old, there were more male users (15.63%) than female users (10.63%). However, from 60 years old and on,

these numbers are inverted, with 25.63% women and 18.76% men.

The diseases that led to the enrollment in the Program are also different in these age groups. From 15 to 49 years old there were more users with traumatic brain injury (TBI) (six cases) when compared to the elderly (two cases). From 60 years old and on, chronic health conditions were predominant, such as: cerebrovascular accidents

(CVA) (42 cases), Alzheimer's Disease (13), Parkinson's Disease (2) and other dementias (6). We observed that the more common diseases relate to chronic-degenerative cases, with 46.26% of the diseases: CVA, Alzheimer's Disease, Parkinson's Disease and Dementias. Then came the diseases related to the quality of care during pregnancy and delivery, with 24.38%: Cerebral Paralysis and Neonatal hypoxia. These diseases can be analyzed according to sex (Table 2).

**Table 2.** Distribution of the users enrolled in the PDUFIM according to sex and disease (n=160).

Disease	Male		Female		Total	
	n	%	n	%	n	%
Cerebrovascular accidents	22	13.75	30	18.75	52	32.50
Cancer	2	1.25	2	1.25	4	2.50
Alzheimer's Disease	4	2.50	9	5.62	13	8.13
Parkinson's Disease	1	0.62	0	0.00	1	0.63
Non-specified Dementias	2	1.25	2	1.25	4	2.50
Vascular Dementia	2	1.25	2	1.25	4	2.50
Mental diseases	2	1.25	2	1.25	4	2.50
Femur fracture	0	0.00	2	1.25	2	1.25
Neonatal Hypoxia	5	3.12	3	1.87	8	5.00
Congestive heart failure/ Cardiomyopathy malformation	0	0.0	1	0.62	1	0.63
Lupus	4	2.5	2	1.25	6	3.75
Cerebral Paralysis	0	0.00	1	0.62	1	0.63
Severe mental retardation	18	11.25	13	8.12	31	19.38
After effects of meningitis	7	4.37	7	4.37	14	8.75
Guillain-Barré Syndrome	1	0.62	1	0.62	2	1.25
Angelman Syndrome	1	0.62	0	0.00	1	0.63
Down Syndrome	0	0.00	1	0.62	1	0.63
Duchenne muscular dystrophy	1	0.62	0	0.00	1	0.63
Traumatic brain injury	1	0.62	0	0.00	1	0.63
Traumatic brain injury	5	3.12	4	2.5	9	5.63
<b>Total</b>	<b>78</b>	<b>48.75</b>	<b>82</b>	<b>51.25</b>	<b>160</b>	<b>100.00</b>

The KPS Scale was applied to 141 cases from 11 units. Two BHU were excluded during this stage because their patient charts were not up-to-date regarding the users of the PDUFIM, the information was incomplete in the process for device acquisition, the charts were illegible, did not present the evolution of the patient and had

inconclusive observations. It is worth mentioning that in one of the excluded units no charts from patients enrolled in the Program could be found. The results of the performance of the users in the KPS according to age group showed that the only user who was not eligible for PC was a child in the 5-9 years old age group, an 8 year old boy who

suffers from urethral abnormal formation with incontinence, due to neuropathic reflex bladder.

The results are described on Table 3, and the BHU were identified by numbers.

**Table 3.** Distribution of the users enrolled in the PDUFIM according to BHU and performance in the KPS (n=141).

BHU	KPS		40		50		60		70		80		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
1	7	4.96	13	9.22	0	0.00	0	0.00	0	0.00	0	0.00	20	14.18
2	1	0.71	5	3.55	2	1.42	1	0.71	0	0.00	0	0.00	9	6.38
3	5	3.55	2	1.42	0	0.00	0	0.00	0	0.00	1	0.71	8	5.67
4	2	1.42	8	5.67	2	1.42	0	0.00	0	0.00	0	0.00	12	8.51
5	10	3.55	26	18.44	2	1.42	0	0.00	0	0.00	0	0.00	38	26.95
6	0	0.00	8	5.67	0	0.00	1	0.71	0	0.00	0	0.00	9	6.38
7	2	1.42	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	2	1.42
8	2	1.42	3	2.13	0	0.00	0	0.00	0	0.00	0	0.00	5	3.55
9	3	2.13	1	0.71	1	0.71	0	0.00	0	0.00	0	0.00	5	3.55
10	7	4.96	5	3.55	1	0.71	0	0.00	0	0.00	0	0.00	13	9.22
11	16	11.35	4	2.84	0	0.00	0	0.00	0	0.00	0	0.00	20	14.18
<b>Total</b>	<b>55</b>	<b>39.01</b>	<b>75</b>	<b>53.2</b>	<b>8</b>	<b>5.67</b>	<b>2</b>	<b>1.42</b>	<b>1</b>	<b>0.71</b>	<b>1</b>	<b>0.71</b>	<b>141</b>	<b>100</b>

The results of the application of KPS at 11 of the 13 BHUs surveyed show that over 90% of people registered at the PDIIUF have a performance below 50%. That is, they are patients admissible for PC, who may be incapacitated or, at least, require frequent help, medical care and special care. On the other hand, patients with KPS performance below 70%, that is, with an early indication of PC assistance, comprise 98.28% of users. Table

4 shows the link between the KPS results and the Spanish Red Cross Scale; we emphasize that a large part of the users was in dependency Grade 5 in the Spanish Red Cross Scale. It should be noted that the Spanish Red Cross Scale results were already available in the medical records of users registered at the PDIIUF, because a Grade 4 or 5 classification is a pre-requisite to incorporate the user in the program.

**Table 4.** The study population (n=141) according to the Karnofsky performance scale result compared to the Spanish Red Cross dependency scale

KPS	Dependency Grade		Grade 3		Grade 4		Grade 5		Total	
	n	%	n	%	n	%	n	%	n	%
40	1	1.82	12	21.82	42	76.36	55	39.00		
50	3	4.05	25	33.78	46	62.16	74	52.48		
60	1	12.50	3	37.50	4	50.00	8	5.67		
70	0	0.00	0	0.00	2	100.00	2	1.42		
80	0	0.00	1	100.00	0	0.00	1	0.71		
<b>Total</b>	<b>5</b>	<b>3.55</b>	<b>41</b>	<b>29.08</b>	<b>94</b>	<b>66.67</b>	<b>141</b>	<b>100.00</b>		

## Discussion

The results show that the studied population was included in the PDIIUF because they present health conditions with a high grade of dependency to perform daily activities and because they need PC, which shows a high percentage of people undergoing PC in PHC. Assessing the functional capacity has been described as an important tool to evaluate the prognosis of the patient's life. Assessing the capacity for everyday life activities may lead to the recommendation of Palliative Care for patients who are dependent for certain activities, such as patients who have an inability to move, inability to eat, or incontinence.<sup>10</sup> In this study, the following pathologies were identified as the most frequent: CVA, cerebral palsy, mental retardation and severe TBI, followed by Alzheimer's disease, Neonatal hypoxia and malformation. These findings do not correspond to the situation of North Somerset (England), where a study performed with patients undergoing PC identified that the most common causes of death in that population were cancer (28%), heart disease (18%), respiratory disease (15%) and dementia (15%).<sup>12</sup>

The results also suggest that the young adult population was the population most affected by these conditions. This finding is consistent with the results of a European study<sup>2</sup> which identified that in Spain, being less than 85 years old is associated with greater chances of undergoing PC; however, in Italy, the same study identified that being less than 65 years old resulted in lower chances of receiving such care. The findings also do not match the results of a study carried out in North Somerset (England) that identified that 84% were above 70 years old.<sup>12</sup> It is worth stressing that differences were identified in these conditions between young adults and elderly people, with prevalence of acute conditions such as TBI in young adults, and chronic conditions in elderly people, such as CVA, Alzheimer's disease, Parkinson's disease and dementia; this fact matches the results of this study. Such differences between the results of this study and the results of European studies may be associated to the

peculiar characteristics of European countries, which may be regarded as countries with a large number of elderly people.

Regarding sex, this study identified a greater number of women undergoing PC. However, it is worth emphasizing that in the age range from 15 to 49 years, there was a greater number of men than women, and a greater number of women from 60 years on. The results of this study match the results of a study carried out in North Somerset, which, by analyzing the deaths of patients undergoing PC, identified that 46% were men and 54% were women.<sup>12</sup> These results match the data from the Brazilian Institute of Geography and Statistics (IBGE) for the region surveyed (Parelheiros), which demonstrate a subtly larger number (50.24%) of women in comparison with the number of men in the region, and a greater number of women above 60 years (2.13%) in comparison with the number of men (1.85%). However, the data show a higher prevalence of women in the age range from 15 to 49 years (28.89%) in comparison with men in this age group (28.17%).<sup>13</sup>

Cancer was not a frequent disease among the studied population. This data is not equivalent to the result of a study conducted in four European countries (Belgium, Italy, Holland, Spain), which has identified that in all countries, except the Netherlands, a cancer diagnosis was a significant predictor for undergoing PC by a specialized team. The authors emphasized the importance of greater attention to patients with other conditions or diseases other than cancer, which end up dying without having access to PC.<sup>2</sup> This finding may be related to the fact that cancer has become a chronic disease, with decrease of mortality and improvements in prospects for treatment and cure. A study<sup>14</sup> pointed out that there is a noticeable drop in deaths from cancer in the South, Southeast and Center-West regions of Brazil, but this drop is only apparent in state capitals: the countryside population rates show a statistically significant increase. This finding matches the result of this study because the city of São Paulo is a major state capital located in the southeast region of the country. Furthermore, comparing these data with

causes of death in the municipality of São Paulo, SP, Brazil, in 2011, 14,041 deaths by neoplasms were identified; 1,208 deaths by Alzheimer disease; and 833 deaths by AIDS. In the region of São Paulo that was surveyed (Parelheiros neighborhood), diseases of the circulatory system have the greatest number of deaths, followed by neoplasms and external causes. Therefore, the results of this study do not match the causes of death in the region studied. However, it is worth noting that, in the region studied, secondary care is deficient, which leads to the hypothesis that there is a late diagnosis of cancer and a rapid evolution to death, which would render impossible the recommendation of palliative care.<sup>15</sup>

Still regarding pathologies, younger users have become dependent of care due to cerebral palsy, neonatal hypoxia, malformations and congenital syndromes. A study<sup>6</sup> carried out with homecare programs in Brazil has identified that the predominant conditions and diseases in children undergoing PC are congenital diseases involving the central nervous system, with a predominance of children between the infant stage and pre-school. The study also identified that all children had similar technological dependencies (gastrostomy and tracheostomy, continuous use drugs and industrialized diet), besides the need for oxygen therapy or noninvasive ventilation. A study<sup>16</sup> showed that these conditions are associated with higher rates of neonatal mortality and that they may indicate inadequacy of obstetric and neonatal care and a lack of impact of intervention programs. Therefore, the still high levels of neonatal mortality in Brazil show the need for a better understanding of the role of assistance in the process of determining health and neonatal morbidity and mortality.

The Karnofsky scale and the Spanish Red Cross Dependency scale showed compatibility when compared, since the most dependent patients (grades 4 and 5 in the Spanish Red Cross dependency scale) also had the worst KPS performance (sum of patients with performance <70%, n=141), comprising, respectively, 96.7% (grade 4) and 97.1% (degree 5) of the study

population. This result stresses the importance and applicability of KPS for the early indication of PC assistance. The WHO recommends that the PC should start as early as possible, preferably from the diagnosis of a progressive disease; however, such procedure is not always possible, but it is advisable that all services for patients that can be included should be prepared for PC.<sup>10</sup> This recommendation reinforces the importance of PHC in the early recognition of these needs. However, in spite of the Brazilian policy proposing a model of de-hospitalization, the predominance of the hospitalocentric model for PC is still evident. This model is inappropriate for not considering the home space as a strong ally in this modality of care.<sup>7</sup> In general, the domicile is usually the preferred place for PC in the opinion of patients and family, that is, patients usually prefer to go to their homes in the terminal phase of the disease.<sup>1,8</sup> A study<sup>2</sup> carried out in four European countries identified that people who die at home are more prone to receive PC than people who die in other locations, such as the hospital. A study<sup>11</sup> with the objective of identifying the preferential location for death in patients with advanced-stage cancer in seven European countries (England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain) has identified that 51% of patients in Portugal and 84% of patients in the Netherlands reported that they would like to die at home. This trend has driven a greater appreciation for the members of the family, who were strongly encouraged to become family caregivers. These caregivers eventually provide great help with domestic tasks, personal care, activities, medications, relief of symptoms, and emotional and existential support.<sup>17</sup>

It is worth noting that the discourse of humanization of care — reflected in the right to receive care together with the family when faced with a disease diagnosis outside therapeutic possibilities — may conceal a serious problem of therapeutic and assistential discontinuity. By identifying the impossibility of cure, the patient is sent home, without due reference to the PHC unit or other home care service.<sup>3</sup> In the Brazilian context, the initiatives focused on home care are

not integrated into the PHC services as is the case in Canada and Spain, which have problems in significantly lower proportion than Brazil regarding funding, criteria for inclusion in the programs, among others.<sup>6</sup> The Brazilian programs focused on domiciliary assistance face difficulties of financing, maintenance, reference and counter-reference and intersectoriality. Such problems are a consequence of the lack of connection of these programs with the PHC, where the health system works in the opposite way: in the direction of high complexity for primary care.<sup>6</sup>

It is known that the PHC plays a fundamental role in the continued care to chronic patients or patients undergoing palliative care, and their relatives, as indicated by the WHO, being the basis for the reference and counter-reference system, ensuring the integration of the continuity of care in the other levels of care.<sup>6</sup> A study with the objective of describing the difficulties of using PC in children at home stressed the importance of planning programs that have the prerequisite of achieving continuous care, avoiding disruptions in care, which shows the commitment of managers with the protection of patients and their family. The study also points out that the planning of a national PC policy must consider the organization of services with full-time actions every day of the week.<sup>18</sup>

Thus, the lack of organization and incorporation of PC to PHC causes harm to patients undergoing PC and their relatives, since studies<sup>17,18</sup> have demonstrated a strong overload on the relatives and caregivers of these patients. A study<sup>7</sup> carried out in Germany, with the objective of identifying the difficulties experienced by caregivers of patients with malignant brain tumor, identified that 59% of families receive no support for home care and that, as a result, 33% showed increased risk of psychosomatic problems, 45% had anxiety, and 33% had an increase in depression levels. The study also demonstrated that the caregiver's quality of life was strongly affected by the difficulties in home care. The professionals who provide medical assistance in hospitals must integrate with the home care team.<sup>1,7</sup> Therefore, an important point to be considered is the need

of identifying and providing support and training to the patient's unpaid caregivers, that is, family and friends. It is important to point out the role of the nurse as a member of the PHC health team in providing support to the patients and their family. The ability to establish a bond and the proximity of these professionals with the people who receive care are strong points of the work with patients and family members in palliative care. Due to the proximity with the family, this professional realizes new possibilities of caring and learns new paths of healthcare assistance.<sup>8</sup> Therefore, the empowerment of chronic patients and their caregivers should be assumed as the new role of PHC nurses, so that they can assume their responsibility in the context of home care.<sup>19</sup>

In the face of the current context of an aging population, there is an increasing need of structuring the health systems to absorb the health demands of the population with quality, considering a restricted budget context. It is crucial to organize care models that include end-of-life care in a structured form and that prioritize, both from the moral and operational point of view, protecting and not abandoning these patients.<sup>1</sup> Therefore, the inclusion of PC in PHC implies the implementation of some actions according to the predicted solvability for this level of care and the coordination of user care, respecting the principles of the WHO and the guarantee of completeness through the organization of the Healthcare Network (HN). Completeness, one of the doctrinal principles of the Brazilian Single Health System (SUS), embraces, doubtlessly, the needs of PC and extends the spectrum of services and actions involved in this assistance. Decree 4,279/2010, from the Brazilian Ministry of Health, specifies the guidelines for the structuring of the HN from the principle of completeness. The HN is defined as organizational arrangements of actions and health services, with different technological densities, integrated through technical, logistical and managerial support systems in order to ensure the completeness of care. It is proposed as a strategy to overcome the fragmentation of care and management, in order to improve the political-institutional operation of SUS and guarantee for

the users the set of actions and services that they need, with effectiveness and efficiency.<sup>20</sup>

The network proposals to support public policies can be a solution to the fundamental problem of SUS: restoring the coherence between the health situation, where there is a strong predominance of chronic conditions, and the health care system. This redevelopment, however, requires profound changes to overcome the current fragmented system. In Brazil, the theme of the HNs is still recent and there are few experiences reported or robust assessments. However, case studies indicate that HNs, similarly to developed countries, can have a significant impact on levels of health.<sup>21</sup> In face of this epidemiological context, there is a huge challenge for the management of the Brazilian Single Health System: creating governance mechanisms that allow a complete care for chronic diseases, such as the situations needing palliative care. The PHC has the task of organizing this network care and promoting communication with the other points of attention.

The characterization of users eligible for PC from the PHC further stresses the importance of keeping the records of patients with chronic conditions always updated and accessible to professionals as an information system that includes all the information on the users, from PHC to hospitalization situations. In order to plan the offer of services, it is necessary to know for sure the needs, where they are allocated and what resources are available. Finally, and in addition to the sharing of information, the study demonstrates the urgent need of organizing the network services, with appropriate communication and a commitment of the parties involved, in order to provide complete, shared and humanized care. It is also important to emphasize the need of carrying out more comprehensive studies focused on the PC at PHC, because of the insufficiency of studies focused on the identification of the population and because this study has the limitation of being carried out with a small population (population serviced at the PDIIUF), a limitation that is a characteristic of case studies.

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