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NECESSIDADES PALIATIVAS NUMA LISTA DE UTENTES DE UMA UNIDADE DE SAÚDE FAMILIAR DE UM CENTRO URBANO


PALLIATIVE NEEDS IN A LIST OF USERS OF A FAMILY HEALTH UNIT FROM AN URBAN CENTER


NECESIDADES PALIATIVAS EN UNA LISTA DE USUARIOS DE UNA UNIDAD DE SALUD FAMILIAR EN UN CENTRO URBANO

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## RESUMO

**Introdução:** A população portuguesa está em processo de envelhecimento prevendo-se que as necessidades paliativas estejam a aumentar. Uma das barreiras ao acesso aos cuidados paliativos é a dificuldade em identificar os utentes que poderiam beneficiar deles. A maioria encontra-se na comunidade, sendo que as equipas dos Cuidados de Saúde Primários estão na melhor posição para os identificar. Diferentes estudos têm avaliado estas necessidades em contexto hospitalar, não tendo sido possível identificar na pesquisa efetuada, estudos nacionais nos Cuidados de Saúde Primários.

**Objetivo:** Avaliar as necessidades paliativas numa lista de utentes de uma Unidade de Saúde Familiar Portuguesa.

**Métodos:** Estudo observacional transversal em utentes com idade igual ou superior a 65 anos provenientes de uma lista de uma Unidade de Saúde Familiar Portuguesa, através da aplicação da escala SPICT-PT™.

**Resultados:** Foram incluídos 188 utentes com idade igual ou superior a 65 anos. A doença cardiovascular foi a principal doença de base (n=57, 30,3%), seguida da doença oncológica (n=31, 16,5%) e da hipertensão (n=28, 14,9%). 50 utentes foram identificados como tendo necessidades paliativas (SPICT-PT™-positivo), os quais apresentavam uma mediana de idade significativamente superior à dos SPICT-PT™-negativos, sem diferenças relativamente ao género. Todos os utentes referenciados à Equipa de Cuidados Paliativos eram SPICT-PT™-positivos.

**Conclusão:** Mais estudos são necessários para avaliar a natureza e a complexidade das necessidades paliativas nos Cuidados de Saúde Primários e as estratégias utilizadas após a sua identificação.

**Palavras-chave:** cuidados paliativos; avaliação de necessidades; cuidados de saúde primários

## ABSTRACT

**Introduction:** The Portuguese population is aging, and palliative needs are expected to increase. One of the barriers to timely access to a palliative care approach is the difficulty in identifying patients who could benefit from them. Most patients with palliative needs are in the community, whereby Primary Health Care teams are in the best position to identify these patients. Different studies have evaluated palliative needs in a hospital context, and to date it has not been possible to identify national studies in Primary Care.

**Objective:** Evaluate palliative needs in a list of patients of a Family Health Unit.

**Methods:** Cross-sectional observational study on a sample of patients aged 65 years or older from a list of a Portuguese Family Health Care, through the application of the SPICT-PT™.

**Results:** A total of 188 patients aged 65 years or older were included. Cardiovascular disease was the most frequent main underlying disease (n=57, 30,3%), followed by oncologic disease (n=31, 16,5%) and hypertension (n=28, 14,9%). 50 patients were identified as having palliative care needs (SPICT-PT™-positive), which had a median age significantly higher than that of the SPICT-PT™-negative, with no statistical differences concerning gender. All the patients referred to the Palliative Care team were SPICT-PT™-positive.

**Conclusion:** More studies are needed to evaluate the nature and complexity of palliative needs in Primary Care and to address the strategies used after the identification of these needs.

**Keywords:** palliative care; needs assessment; primary health care; family practice

## RESUMEN

**Introducción:** La población portuguesa está envejeciendo y se espera que aumenten las necesidades paliativas. Una de las barreras para acceder a los cuidados paliativos es la dificultad para identificar a los usuarios que podrían beneficiarse de ellos. La mayoría se encuentran en la comunidad y los equipos de Atención Primaria de Salud están en la mejor posición para identificarlos. Diferentes estudios han evaluado estas necesidades en el contexto hospitalario, y aún no ha sido posible identificar estudios nacionales en Atención Primaria de Salud.

**Objetivo:** Evaluar necesidades paliativas en un listado de usuarios de una Unidad de Salud de Familia.

**Métodos:** Estudio observacional transversal en usuarios de 65 años o más de un listado de una Unidad de Salud de Familia Portuguesa, utilizando la escala SPICT-PT™.

**Resultados:** Se incluyeron 188 usuarios de 65 años o más. La enfermedad cardiovascular fue la principal enfermedad de base (n=57, 30,3%), seguida de la enfermedad oncológica (n=31, 16,5%) y la hipertensión (n=28, 14,9%). Se identificaron 50 usuarios con necesidades paliativas (SPICT-PT™-positivo), los cuales tienen una mediana de edad significativamente mayor que el SPICT-PT™-negativo, sin diferencias en cuanto al género. Todos los usuarios remitidos al equipo de cuidados paliativos fueron positivos para SPICT-PT™.

**Conclusión:** Se necesitan más estudios para evaluar la naturaleza y complejidad de las necesidades paliativas en Atención Primaria de Salud y las estrategias utilizadas después de su identificación.

**Palabras clave:** cuidados paliativo; evaluación de necesidades; atención primaria de salud

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## INTRODUCTION

The population is aging, leading to an increase in the number of chronic diseases and average life expectancy (INE,2023). In Europe, 85% of the population currently dies from chronic diseases such as cancer, cardiovascular disease, or dementia. Chronic diseases are characterized by their slow progression, fluctuations in disease trajectory, long duration, and uncertain prognosis. Therefore, it is a great challenge to treat chronic diseases for an increasingly longer period, until very advanced stages of their progression (Divo et al, 2014). In the advanced stages of chronic disease, patients normally suffer from pain and other physical and psychological symptoms, so they could benefit from a palliative care approach (Moens et al, 2014; Barbosa A, 2006). It is therefore essential to identify patients who could need this approach, which englobes physical, psychological, social, and spiritual care, to promote quality of life in all its aspects (SPICT-PT™, 2019).

There is evidence from randomized controlled trials that early access to specialized palliative care can promote quality of life, reduce time of hospital admission and hospitalizations, and even prolong survival (Vanbutsele et al, 2018; Kavalieratos et al, 2016). However, recent evidence shows that palliative care typically arrives late in the disease trajectory and access to palliative care is unequal (Allsop et al, 2018; Mason et al, 2018).

The patients with palliative needs are in hospitals and long-term care units, but especially in the community, so Primary Health Care teams are in the best position to identify these patients. Indeed, the needs of approximately 85-90% of people at the end of life can be met with primary palliative care provided by family doctors (Afshar et al, 2020).

One of the barriers to timely access to palliative care is the difficulty in the identification of patients who could benefit from them and defining the right time to do so (Hawley, 2018). The identification process should not be based solely on predicting mortality or survival but must also focus on anticipating needs whenever they occur and predicting the course of functional decline to trigger a holistic assessment and develop a proactive palliative care plan (ElMokhallalati et al, 2020). The SPIC™-PT is a clinical tool that supports the identification of patients who might benefit from a palliative care approach, the planning of future care and can be used in different settings (SPICT-PT™, 2019)

National and international studies have evaluated palliative needs in a hospital context (Bourmorck et al, 2023; De-Bock et al, 2018; Gómez-Batiste et al, 2014; Hamano et al, 2018; Hamano et al, 2019; Hightet et al 2013; Martins, 2020; Piers et al, 2021; Wijmen et al, 2020), and to date, it has not been possible to identify national studies within the scope of Primary Care, which makes it extremely important to carry out a study in this area.

This study aims to evaluate palliative needs in a list of patients of a Portuguese Family Health Unit.

## 1. METHODS

A single-center observational, cross-sectional study was conducted in a Portuguese Family Health Unit. The protocol was submitted for consideration of the Health Ethics Committee (reference nr. 112/CES/JAS) and the Local Information Protection and Security Committee, by which it was approved. Informed consent was dispensed by the Local Information Protection and Security Committee.

### 1.1 Sample

We included patients aged 65 years or older from a family physician's list. Patients who had face-to-face or non-face-to-face contact with the family health team during the study period were included, up to the representative sample size, which was determined considering a confidence interval of 95% and a precision level of 5%, from the total number of patients on the aforementioned list, at the date of data collection.

Patients with a record of last contact with the family health team exceeding 2 years ago were excluded.

### 1.2 Data collection instruments

A convenience sample of patients that contacted the family physician during the study period was asked to participate in this study. The SPIC™-PT™ tool, 1st and 2nd part, was applied, as well as a collection of sociodemographic data (age, gender, institutionalization or not, level of independence through the Barthel index and main underlying disease).

The SPIC™ tool helps identify patients with deteriorating health due to serious illness or advanced conditions, prompting holistic assessment and future care planning. SPIC™ is available in multiple translations including Portuguese (SPICT-PT™), by the authors Mariana Mira e Paulo Reis-Pina (<https://www.spict.org.uk/the-spict/spict-pt/>), its use having been authorized by both authors. Palliative care needs are considered whenever we have at least two general indicators (1st part) and at least one clinical indicator (2nd part).

### 1.3 Statistical Analysis

A descriptive analysis was carried out to evaluate the frequencies of the variables in the sample, followed by an inferential analysis to look for significant relationships between them. Nominal variables were evaluated in terms of absolute frequencies and percentage of each category, while continuous variables were evaluated in terms of minimum and maximum values, median and

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interquartile range. Categorical variables were expressed as counts and percentages and were compared with Pearson’s chi-square test or Fisher exact test as appropriate. The chi-squared test was used to compare the nominal variables between groups. Binomial analysis was also performed. The analyses were completed using IBM SPSS®, version 27.0 (IBM Corporation, NY, USA). A p-value of less than 0.05 was considered statistically significant.

## 2. RESULTS

### 2.1 Sociodemographic characterization

A total of 188 patients aged 65 years or older were included during the study period, of which 56,9% were male. Table 1 shows patients’ characteristics. Cardiovascular disease was the most frequent main underlying disease in the total sample (n=57, 30,3%), followed by oncologic disease (n=31, 16,5%) and hypertension (n=28, 14,9%).

**Table 1** – Characteristics of the included patients.

	TOTAL (n=188)	SPICT-PT™ positive (n=50)	SPICT-PT™ negative (n=138)	p-value
Age, years – median (IQR)	73,0 (65-94)	80,0 (66 – 94)	71,5 (65 – 92)	<0,001*
Gender				0,249 <sup>‡</sup>
Male, n (%)	107 (56,9)	25 (50)	82 (59,4)	
Female, n (%)	81 (43,1)	25 (50)	56 (40,6)	
Main underlying disease, n (%)				0,002 <sup>‡</sup>
Oncologic disease	31 (16,5)	11 (22,0)	20 (14,5)	
CV disease (not hypertension)	57 (30,3)	21 (42,0)	36 (26,1)	
Neurologic disease	3 (1,6)	2 (4,0)	1 (0,7)	
Dementia	4 (2,1)	4 (8,0)	0 (0,0)	
Infectious disease	1 (0,5)	1 (2,0)	0 (0,0)	
Musculoskeletal disease	22 (11,7)	3 (6,0)	19 (13,8)	
Kidney disease	3 (1,6)	0 (0,0)	3 (2,2)	
Respiratory disease	9 (4,8)	1 (2,0)	8 (5,8)	
Endocrine disease (not diabetes)	3 (1,6)	0 (0,0)	3 (2,2)	
Psychiatric disease	6 (3,2)	1 (2,0)	5 (3,6)	
Digestive disease	2 (1,1)	1 (2,0)	1 (0,7)	
Hypertension	28 (14,9)	2 (4,0)	26 (18,8)	
Diabetes	18 (9,6)	3 (6,0)	15 (10,9)	
Other	1 (0,5)	0 (0,0)	1 (0,7)	
Institutionalization, n (%)				0,009 <sup>†</sup>
Yes	11 (5,9)	7 (14,0)	4 (2,9)	
No	177 (94,1)	43 (86,0)	134 (97,1)	
Barthel index, n (%)				<0,001 <sup>†</sup>
0-20 (total dependency)	3 (1,6)	3 (6,0)	0 (0,0)	
21-60 (severe dependency)	13 (6,9)	13 (26,0)	0 (0,0)	
61-90 (moderate dependency)	41 (21,8)	23 (46,0)	17 (12,3)	
91-99 (slight dependency)	10 (5,3)	6 (12,0)	5 (3,6)	
100 (independent)	121 (64,4)	5 (10,0)	116 (84,1)	
Palliative Care team referral, n (%)	5 (2,7)	5 (10,0)	0 (0,0)	

IQR – interquartile range; CV – cardiovascular; \*Mann-Whitney non-parametric test for independent samples; <sup>‡</sup>Pearson’s Chi-square test; <sup>†</sup>Fisher’s exact test.

### 2.2 Characterization of the patients with palliative care needs

Of the study population, 50 patients (26,5%) were identified as having palliative care needs (SPICT-PT™-positive) (Table 1). The median age of the SP ICT-PT™-positive was significantly higher than that of the SP ICT-PT™-negative (80,0 vs 71,5, p<0,001). There were no statistical differences concerning gender (p=0,249). As mentioned above, cardiovascular disease was the main underlying disease in both groups. The second most frequent condition in SP ICT-PT™-positive patients was oncologic disease. We found statistically significant differences when analysing the association between the SP ICT-PT™ scale and the main underlying disease (p=0,002).

We performed a simple linear regression to test if a positive score was associated with specific groups of diseases, but it was not possible to affirm that. A binomial analysis was performed to evaluate the proportion of positive scores among groups of diseases, and we found that negative scores are higher in groups of diseases like hypertension (26/2, p<0.001), diabetes (15/3, p=0.008), respiratory diseases (8/1, p=0.039) and musculoskeletal disease (19/3, p<0.001). From this study sample, 11 patients (5,9%) were institutionalized. Among institutionalized patients, 63,66% were SP ICT-PT™-positive while among non-institutionalized patients

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26,3% were SPICT-PT™-positive. Regarding the dependence level, we also found significant differences between SPICT-PT™-positive and SPICT-PT™-negative patients ( $p < 0,001$ ).

From the analysis of the SPICT-PT™-positive patients, we observed that the most frequent general indicators were “depends on others for care due to increasing physical and/or mental health problems” (84%), followed by “persistent symptoms, despite optimized treatment for the underlying condition(s)” (68%). The lowest prevalence was the indicator concerning the request from patients or families for palliative care (10%). Regarding specific indicators, the most frequent among SPICT-PT™-positive patients were “not able to communicate by speaking; little social interaction” (58%) followed by “urinary and faecal incontinence” (50%).

### 2.3 Characterization of the patients referred to the Palliative Care team

In addition to the described data, we carried out an analysis of the patients referred to the Palliative Care team. As we can see in Table 1, all the patients referred to the Palliative Care team were SPICT-PT™-positive. Oncologic disease was the most frequent condition of the patients referred (60%). We found no statistically significant differences between referred and non-referred patients regarding age (median), gender, and main underlying disease (Table 2). However, as expected, patients referred to the Palliative Care team have a significantly higher level of dependency ( $p < 0,001$ ).

**Table 2** – Characteristics of the patients referred and non-referred to the Palliative Care team

	Referred	Non-referred	p-value
Age, years – median (IQR)	80 (79-90)	73 (65 – 94)	0,059*
Gender, n (%)			0,653 <sup>‡</sup>
Male	2 (1,1)	105 (55,9)	
Female	3 (1,6)	78 (41,5)	
Main underlying disease, n (%)			0,209 <sup>‡</sup>
Oncologic disease	3 (60,0)	28 (15,3)	
CV disease (not hypertension)	1 (20,0)	56 (30,6)	
Neurologic disease	1 (20,0)	2 (1,1)	
Dementia	0 (0,0)	4 (2,2)	
Infectious disease	0 (0,0)	1 (0,5)	
Musculoskeletal disease	0 (0,0)	22 (12,0)	
Kidney disease	0 (0,0)	3 (1,6)	
Respiratory disease	0 (0,0)	9 (4,9)	
Endocrine disease (not diabetes)	0 (0,0)	3 (1,6)	
Psychiatric disease	0 (0,0)	6 (3,3)	
Digestive disease	0 (0,0)	2 (1,1)	
Hypertension	0 (0,0)	28 (15,3)	
Diabetes	0 (0,0)	18 (9,8)	
Other	0 (0,0)	1 (0,5)	
Dependency level (Barthel index)			<0,001 <sup>†</sup>
Mean	50	92,7	
Median	60	100	

\*Median test for independent samples. <sup>‡</sup>Fisher’s exact test; <sup>†</sup>Mann-Whitney non-parametric test for independent samples.

### 3. DISCUSSION

To our knowledge, this was the first study that addressed palliative needs in Primary Health Care in Portugal using the SPICT-PT™ tool. Around a quarter of the assessed patients aged 65 or older have palliative needs. A study carried out in Primary Health Care in Japan, also using the SPICT scale, showed that 17.3% of patients had palliative needs, although they used a different cut-off point to that used in this study, meaning that a direct comparison of the results cannot be made (Hamano et al, 2019). Another study, which used the NECPAL scale associated with the Surprise Question, showed that around 8% of patients over the age of 65 presented palliative needs (Gómez-Batiste et al, 2014). Our study, which includes both face-to-face contacts and non-face-to-face contacts may explain this value, which is higher than those found in the literature.

The general practitioner's (GP) knowledge of the health status of their patients, as well as a closer monitoring of both their patients and their families, inherent to Family Medicine, allows for a more reliable assessment of the current health status, even through non-face-to-face contacts with your family healthcare team.

Non-oncological diseases represented a large proportion of patients with palliative needs, which reflects the heterogeneity of the primary care population, as seen in the literature (Gómez-Batiste et al, 2014; Hamano et al, 2018, Hamano et al, 2019).

Of the patients with palliative needs identified, 10% were referred to the Palliative Care Team. The identification of palliative needs, as we know, does not mean the need for referral to a team specialized in Palliative Care, but rather the need to initiate a process of promoting discussion with patients and their families, to plan the adequacy of future care. It also demonstrates the importance of timely identification of patients who benefit from palliative care integrated into their general care, to better adapt the care provided by family health teams, using palliative care principles in their clinical practice.

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In our study, of the 11 institutionalized patients, seven (63,6%) had palliative needs and none of them were referred to a Palliative Care Team. Although it was not specifically addressed in this study, the question remains whether the GP would consider that these users will have greater monitoring and support, namely by a nursing team in the institutions, or if the palliative needs they do have, do not motivate referral to a palliative care team. As we know, the causes for institutionalization could be social issues or lack of family support, and not due to multimorbidity or chronic illnesses at the end of life. In fact, although these patients had a mean age of 82,4 years, 63,6% of them had a Barthel score of at least 75 points. Further investigation is needed to understand how and to what extent institutionalized patients access palliative care.

Of the users who were referred to a Palliative Care Team, 60% had oncological disease. However, given that the number was too small, it does not allow for the drawing of conclusions and/or generalizations.

Our results and the lack of studies in the Primary Care only allow us to speculate about the advantages of early identification of palliative needs. The authors believe that it will allow the GP to be more aware to these patients, anticipating care that will predictably be necessary, whether in clinical, family, economic or social terms. It also allows the GP to introduce primary palliative interventions as conversations about advanced care planning especially with non-oncological patients that have a more uncertain disease trajectory, involving patients and families in decision making processes.

By carrying out this study, we verified that the SPICT-PT™ tool is easy to use and quick to complete, which could represent a helpful instrument for Family Medicine in identifying patients with palliative needs and in initiating the palliative approach, offering a starting point for introducing advanced care planning.

Despite the innovative results and this being the first study to apply the SPICT-PT tool in a community setting in Portugal, some limitations must be highlighted. The most important limitation was the restriction of the population to a small sample from a list of patients of a general practice unit, a sample limited to patients who contacted their unit during the study period and not randomized, which makes it difficult to generalize the results. More studies will be needed, particularly comparing rural communities and urban areas or other geographic areas, based on different lists of patients and with randomized samples, to analyze and compare the results of this study. On the other hand, the restriction in this study to a population over 65 years of age limited the identification of palliative needs in younger patients, so further studies will also be needed to understand palliative needs in these age groups. It is also of interest to understand what kind of actions are initiated after the identification of patients with palliative needs as well as the nature and complexity of those needs.

Although primary care providers are pivotal in the generalized provision of palliative care, barriers to achieving that can be identified. Barriers reported by primary care providers include bureaucratic procedures, communication difficulties and lack of skills or confidence (Carey, 2019). Growing demands on palliative care delivery will pose a challenge in future years for health systems to adapt to changes in population needs (Etkins et al, 2017).

## CONCLUSION

Of the study population, 50 patients (26,5%) were identified as having palliative care needs, and 10% of which were referred to palliative care. Traditionally it is easier to identify palliative needs in oncological patients since the disease's trajectory is easier to predict. However, non-oncological diseases, especially in primary care, represent many patients with palliative needs that need to be addressed timely.

General practitioners have a privileged position to identify patients with palliative needs due to their knowledge of their health conditions and their social, emotional, and familiar circumstances. Referral to palliative care should be analysed in context, depending on the availability of Community Palliative Care Teams.

This study opens an opportunity to better evaluate the needs of patients facing life threatening conditions in the community and further investigation is needed to understand the nature of the identified needs and its complexity.

## AUTHOR CONTRIBUTIONS

Conceptualization, D.P., E.F., T.C., I.G. and C.R.; data curation, D.P., E.F. and L.S.; formal analysis, E.F. and L.S.; investigation, D.P., E.F. and T.C.; methodology, D.P., E.F. and T.C.; project administration, D.P. and E.F.; resources, T.C. and C.R.; supervision, T.C., I.G. and C.R.; validation, D.P. and E.F.; visualization, D.P.; writing-original draft, D.P. and E.F.; writing-review and editing, D.P., E.F., T.C., I.G. and C.R.

## CONFLICTS OF INTEREST

The authors declare no conflict of interest.



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