

Palliative Care Needs in Primary Health Care: Characteristics of Patients with Advanced Cancer and Dementia

Necessidades Paliativas em Cuidados de Saúde Primários: Características dos Doentes com Neoplasia e Demência Avançadas

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Acta Med Port 2024 Feb;37(2):90-99 ▪ <https://doi.org/10.20344/amp.20049>

ABSTRACT

Introduction: The increase in life expectancy brought a higher prevalence of chronic diseases, with an emphasis on those who reached advanced stages and required palliative care. We aimed to characterize patients diagnosed with advanced neoplasms and/or dementia accompanied in primary health care and to test the sensitivity of two tools for identifying patients with palliative needs.

Methods: We recruited three voluntary family physicians who provided data relative to 623 patients with active codification for neoplasm and/or dementia on the MIM@UF platform. We defined 'patient with palliative needs' as any patient with this codification in advanced stadium and made their clinical and sociodemographic characterization. Assuming the existence of advanced-stage disease as the gold standard, we calculated and compared the sensitivities of each of the tools under study: the surprise question, the question 'do you think this patient has palliative needs?' and an instrument that corresponded to identification by at least one of the questions.

Results: Among the analyzed data, there were 559 (89.7%) active codifications of neoplasm and 64 (10.3%) of dementia; the prevalence of advanced neoplasm and dementia was 1.0% in the studied sample. The subgroup of patients with advanced dementia showed female sex predominance, an older age, and less access to health care. In both subgroups there was a scarcity of data related to education and income, and we observed polypharmacotherapy and multimorbidity. The sensitivity of the surprise question was 33.3% for neoplasm and 69.3% for dementia; of the new tool 50.0% for neoplasm and 92.3% for dementia; and, when used together, 55.6% for neoplasm and 92.3% for dementia.

Conclusion: Our results help characterize two subpopulations of patients in need of palliative care and advance with a possible tool for their identification, to be confirmed in a representative sample.

Keywords: Dementia; Neoplasms; Palliative Care; Primary Health Care

RESUMO

Introdução: O aumento da esperança de vida trouxe maior prevalência de doenças crónicas, merecendo destaque as que atingem estádios avançados e que requerem cuidados paliativos. Pretendeu-se caracterizar os doentes com diagnóstico de neoplasia e/ou demência em estágio avançado, acompanhados em cuidados de saúde primários, e testar a sensibilidade de duas ferramentas para identificação de doentes com necessidades paliativas.

Métodos: Recrutámos três médicos de família voluntários que forneceram dados relativos a 623 doentes com codificação ativa de neoplasia e/ou demência na plataforma MIM@UF. Definimos como 'doente com necessidades paliativas' todo o doente com doença em estágio avançado, e fizemos a sua caracterização clínica e sociodemográfica. Assumindo como *gold standard* a existência de doença em estágio avançado, calculámos e comparámos as sensibilidades de cada uma das ferramentas em estudo: a questão surpresa, a questão 'acha que este doente tem necessidades paliativas?' e um instrumento que correspondesse a identificação por pelo menos uma das questões.

Resultados: De entre os dados analisados, existiram 559 (89,7%) codificações ativas de neoplasia e 64 (10,3%) de demência; a prevalência de neoplasia e demência avançadas foi de 1,0% na amostra estudada. O subgrupo de doentes com demência avançada mostrou predomínio do sexo feminino, idade superior e menor acesso a cuidados de saúde. Em ambos os subgrupos houve escassez de dados relativos à escolaridade e rendimento e observámos polifarmacoterapia e multimorbilidade. A sensibilidade da questão surpresa foi de 33,3% para neoplasia e 69,3% para demência; da nova ferramenta de 50,0% para neoplasia e 92,3% para demência; e, quando usadas em conjunto, de 55,6% para neoplasia e 92,3% para demência.

Conclusão: Estes resultados ajudam a caracterizar duas subpopulações de doentes com necessidade de cuidados paliativos e avançam com uma possível ferramenta para sua identificação, a confirmar a sua utilidade numa amostra representativa.

Palavras-chave: Cuidados de Saúde Primários; Cuidados Paliativos; Demência; Neoplasias

INTRODUCTION

The progress of medicine throughout the past century has led to an increased average life expectancy and a re-configuration of the demographic composition of populations.¹ In addition, there was an increased prevalence of diseases associated with ageing, including dementia and neoplastic disease,² representing a major challenge in the provision of healthcare, mainly palliative care,³ defined

by the World Health Organization (WHO) as an approach aimed at improving the quality of life of patients and families facing problems related to life-threatening illness.⁴

In fact, an estimated 56.8 million people worldwide are in need for palliative care each year, according to the same organisation.⁴ In Portugal, it is estimated that between 81,553 and 96,918 adults were in need for this care in 2020.⁵

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Recebido/Received: 15/04/2023 - Aceite/Accepted: 30/05/2023 - Publicado Online/Published Online: 10/08/2023 - Publicado/Publicado: 01/02/2024

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However, most patients do not have access to palliative care, with an assessment showing only a 24.9% coverage of patients with potential palliative care needs (PPCN).⁶

Different studies have shown that the earlier the access to this type of care, the better the quality of life,⁷⁻⁹ the less aggressive the treatment and the greater the survival when compared to access within the standard time window for this treatment.⁷

A timely identification of patients with PPCN is therefore crucial. The surprise question (SQ),¹⁰ translated and validated into Portuguese,¹¹ is a tool aimed at this identification, with a 63.9% (48.2% - 79.6%) and 67.3% (60.1% - 74.4%) sensitivity and specificity, respectively, with a 29.9% (19.6% - 40.1%) positive predictive value and a 89.5% (84.1% - 94.9%) negative predictive value.¹² Considering the estimated prevalence of patients with PPCN, there seems to be room and need for improvement in the quality and effectiveness of this identification.

In this regard, the integration of primary care physicians in the provision of palliative care is of great importance: physicians look after patients and families, including during home visits and are usually the first point of contact of patients with healthcare.¹³ Their holistic approach is also crucial and, as described in a WHO document, both care modalities share some essential values, including equity, universal access to healthcare services, and community participation in healthcare.¹⁴ The same document has described that the provision of palliative care by primary care physicians prevents and alleviates the suffering caused by severe and complex disorders (through symptomatic relief, for example), reduces the number and duration of hospitalisations, protects against financial risk situations and ensures universal healthcare coverage.¹⁴ For this very reason, it is expected that the provision of palliative care by primary care physicians will be increased in the future¹⁵; in fact, a 1.5% prevalence of patients with PPCN in the whole population and 8.0% in the group of patients aged 65+ is described by literature.¹⁶ A 17.3% prevalence was found in the population aged 65+ by a primary care evaluation.¹⁷

This study was aimed at assessing patients attending primary care and diagnosed with neoplastic disease and/or advanced dementia. Subsequently, assuming these criteria (the presence of advanced disease) as gold standard, the study was mainly aimed at assessing the sensitivity of the SQ in our group of patients, as well as a new question - 'do you think this is a patient with potential palliative care needs?' (NQ) - comparing the results of both questions in isolation and when combined.

METHODS

Study design

This exploratory study was aimed at the identification and characterisation of patients with PPCN presenting with neoplastic disease and/or dementia as recorded in the patient's clinical files and attending the physicians involved, as part of a project aimed at characterising the patients with advanced disease attending primary care. The study was approved by the Ethics Committee of the *Associação Regional de Saúde do Centro* (ARS Centro) (opinion reference number 42/2022).

All the physicians who participated in the study were explained about the aims and were asked their informed consent before data were collected.

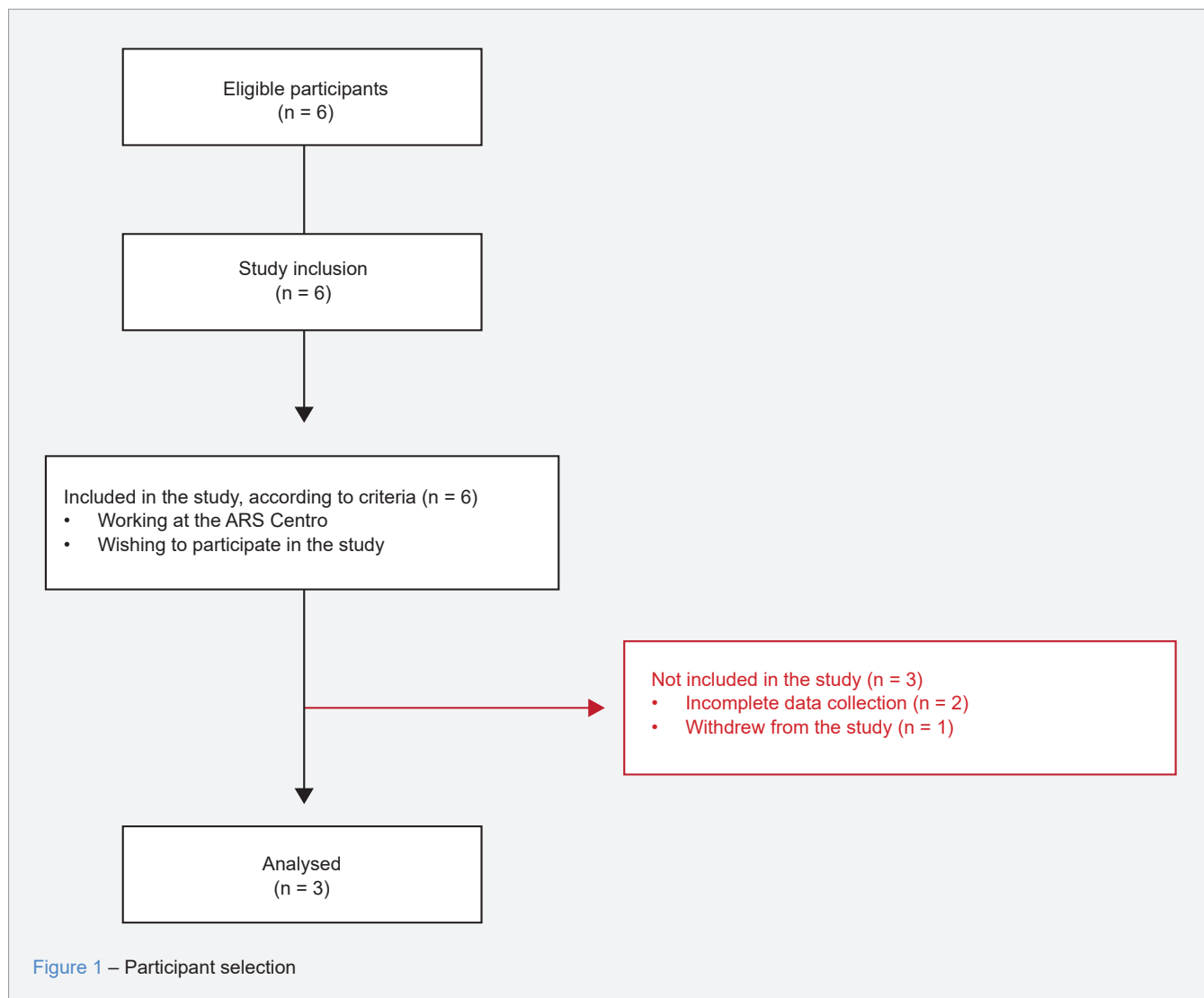
Selection of participants

An e-mail with the study presentation and participation request was sent to some of the physicians working at the ARS Centro. This mailing list included physicians who have already shown an interest in collaborating with the research carried out at the Faculty of Medicine of the University of Coimbra. All physicians who met the following criteria were included: (i) working at the ARS Centro and (ii) showing an interest in taking part in the project. In addition, the participation of each unit was approved by the functional unit coordinator. In total, six physicians - working at the Coimbra Sul (Cândido Figueiredo, Vitrius, Infante D. Henrique and Lusitana Family Health Units) and working at the ARS Centro - gave their consent for the participation in the study, providing data on 623 disease codes. It should be noted that, during the data collection process, one of the participants withdrew from participating in the work for personal reasons, and two participants did not complete data collection. Therefore, data were provided by three physicians (Fig. 1).

Data collection

'PPCN due to neoplasm or dementia' included patients presenting with active coding for advanced stage neoplasm (defined as neoplasm with active secondary location/'metastatic neoplasm') and/or advanced stage dementia (defined as complete functional dependence, i.e., patients totally dependent on a third person to carry out their activities of daily living, assessed using the Barthel scale), according to clinical records.

Using the MIM@UF platform, all the active neoplasm and/or dementia codes were identified in clinical records of the participating physicians



(Appendix 1: <https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/20049/15195>). Subsequently, by accessing the clinical records of the patients with these codes, the presence of any of the pathologies at an advanced stage was assessed. A set of sociodemographic data (gender, age, marital status, education, and income) and clinical data (active chronic diseases, drugs recorded as chronic medication, medical appointments over the past year in primary care and in secondary care). Income was assessed with the Socioeconomic Deprivation Index (SEDI), validated for use in primary care, aimed at the socioeconomic assessment.¹⁸ A database was developed from this by filling in a form sent to participants. All data were obtained by accessing the MIM@UF, SClínico® and RSE computing platforms.

A total of 30 patients with PPCN presenting with neoplastic disease and/or dementia were randomly selected, and their attending physicians were asked two questions: SQ and NQ. Responses, as well as collected data were anonymously recorded and analysed.

The total number of patients on each physician's list was also obtained to obtain the prevalence of advanced disease in this group of patients.

Considering the presence of advanced disease as gold standard, the sensitivities for the identification of patients with PPCN with each question alone and with an instrument that corresponded to the identification by at least one of the questions were calculated and compared.

Table 1 – Prevalence of advanced disease

Among coded patients	Relative frequency of advanced disease			Total (n = 623)
Pathology	n (%)			n (%)
Advanced neoplasm	26 (4.7%)			559 (89.7%)
Advanced dementia	29 (45.3%)			64 (10.3%)
Among the whole patient population	Participant 1 (n = 1,654)	Participant 2 (n = 1,711)	Participant 3 (n = 1,800)	Total (n = 5,165)
Pathology	n (%)	n (%)	n (%)	n (%)
Advanced neoplasm and dementia	30 (1.8%)	11 (0.6%)	12 (0.7%)	53 (1.0%)
Advanced disease	68 (4.1%)	18 (1.1%)	20 (1.1%)	106 (2.1%)

Data analysis

Data analysis was carried out by presenting means and standard deviations (scalar variables) and relative frequencies for nominal and ordinal variables.

The sensitivity of the instruments was obtained using the presence of advanced disease as gold standard according to criteria. The following formula was used for this calculation: $[\text{true positives}/(\text{true positives} + \text{false negatives})]$.

RESULTS

Characterisation of patients presenting with neoplasm and dementia

Data on 623 active neoplasm and dementia codes were obtained, including 559 (89.7%) regarding neoplasms, and 64 (10.3%) regarding dementia (Table 1). Detailed data for the five systems with the highest prevalence of neoplasm can be found in Appendix 2 (Appendix 2: <https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/20049/15196>).

A total of 55 (8.8%; n = 623) advanced neoplasm and dementia codes were identified, from which 29 (45.3%; n = 64) were diagnosed with dementia and 26 (4.7%; n = 559) with neoplasm (Table 1).

Throughout the project, 106 patients with PPCN were identified, including 53 patients presenting with neoplasms and/or dementia. The total number of patients on the physicians' lists was 5,165, so 1.0% was the prevalence of advanced neoplasm and dementia in our group of patients and 2.1% was the overall prevalence of advanced disease (Table 1).

Characteristics of patients

Patients with advanced neoplasm

A total of 26 patients presenting with advanced neoplasm

were identified, with a mean age of 68.1 years (minimum age of 36 and maximum of 90) and equally distributed by gender [13 (50.0%) patients]. Data on education were unavailable regarding 25 (96.2%) of the patients, and primary education was recorded for the only patient with this data. Similarly, data on income were also unavailable regarding 21 (80.8%) of the 26 patients; as regards the remaining patients, 4 (15.4%) had a SEDI 1 classification and 1 (3.8%) had a SEDI 2, with no patients ranked as SEDI 3. In terms of clinical characteristics, each patient presented, on average, with 5.2 active chronic diseases and were treated with 6.8 drugs as chronic medication, having attended 7.4 primary care consultations and 10.0 secondary care medical appointments throughout the past year (Table 2).

Patients with advanced dementia

Data from 29 patients with advanced dementia were obtained, with an average age of 83.3 years (with a minimum age of 71 and a maximum of 97) and a female predominance (20; 69.0%). Data on education were unavailable regarding 25 (86.2%) of the patients, while primary education was recorded for the remaining 4 (13.8%) patients. Data on the patients' income were also unavailable regarding 18 (62.1%) patients, while 7 (24.1%) were ranked as SEDI 1 and 4 (13.8%) as SEDI 2, with no patients ranked as SEDI 3. In terms of clinical characteristics, patients presented with an average of 5.1 active chronic diseases, and were on 7.5 drugs as chronic medication, while each patient attended 3.8 primary care consultations and 1.5 secondary care medical appointments throughout the past year (Table 2).

Sensitivity of the instruments used in the study

As shown in Table 3, a 48.2% sensitivity was obtained

Table 2 – Characteristics of the patients presenting with advanced neoplasm and dementia

Advanced neoplasm (n = 26)	n (%)	Advanced dementia (n = 29)	n (%)
Gender		Gender	
Female	13 (50.0%)	Female	20 (69.0%)
Male	13 (50.0%)	Male	9 (31.0%)
Age		Age	
Mean	68.1	Mean	83.3
Standard deviation	13.3	Standard deviation	7.0
Minimum	36	Minimum	71
Maximum	90	Maximum	97
Marital status		Marital status	
Single	0 (0.0%)	Single	0 (0.0%)
Married	18 (69.2%)	Married	14 (48.3%)
Widowed	2 (7.7%)	Widowed	3 (10.3%)
Divorced	0 (0.0%)	Divorced	0 (0.0%)
No information	6 (23.1%)	No information	12 (41.4%)
Education		Education	
Primary	1 (3.8%)	Primary	4 (13.8%)
Basic	0 (0.0%)	Basic	0 (0.0%)
Secondary	0 (0.0%)	Secondary	0 (0.0%)
High	0 (0.0%)	High	0 (0.0%)
No information	25 (96.2%)	No information	25 (86.2%)
Income		Income	
SEDI 0	0 (0.0%)	SEDI 0	0 (0.0%)
SEDI 1	4 (15.4%)	SEDI 1	7 (24.1%)
SEDI 2	1 (3.8%)	SEDI 2	4 (13.8%)
SEDI 3	0 (0.0%)	SEDI 3	0 (0.0%)
No information	21 (80.8%)	No information	18 (62.1%)
No. of active chronic diseases		No. of active chronic diseases	
Mean	5.2	Mean	5.1
Standard deviation	2.4	Standard deviation	1.5
Minimum	1	Minimum	2
Maximum	12	Maximum	8
No. of drugs as chronic medication		No. of drugs as chronic medication	
Mean	6.8	Mean	7.5
Standard deviation	3.4	Standard deviation	2.4
Minimum	1	Minimum	4
Maximum	14	Maximum	12
No. of medical appointments over the past year in primary care		No. of medical appointments over the past year in primary care	
Mean	7.4	Mean	3.8
Standard deviation	5.9	Standard deviation	3.2
Minimum	0	Minimum	0
Maximum	20	Maximum	10
No. of medical appointments over the past year in secondary care		No. of medical appointments over the past year in secondary care	
Mean	10.0	Mean	1.5
Standard deviation	9.8	Standard deviation	2.2
Minimum	0	Minimum	0
Maximum	41	Maximum	8

SEDI: Socioeconomic Deprivation Index.

Table 3 – Tool sensitivity

	Advanced disease	Advanced neoplasm	Advanced dementia
SQ	48.2%	33.3%	69.2%
NQ	58.9%	50.0%	92.3%
SQ and NQ	64.2%	55.6%	92.3%

SQ: surprise question; NQ: new question ('do you think this is a patient with potential palliative care needs?')

for the SQ regarding all the patients with PPCN in our group, and a 58.9% for the NQ; 64.2% of the patients with PPCN were identified with the combined use of both instruments.

In detail, as regards advanced neoplasm, a 33.3% sensitivity was obtained for the SQ, 50.0% for NQ and 55.6% for the use of both questions combined. On the other hand, a 69.2% sensitivity for SQ, 92.3% for NQ and 92.3% for both tools were shown for dementia.

DISCUSSION

This study was aimed at assessing the sensitivity of a new tool for the identification of patients with PPCN, in isolation and combined with the SQ in two different populations of patients with potential palliative needs.

As it is well known, the early implementation of palliative care leads to the improvement in patients' quality of life⁷⁻⁹, requiring a timely identification. The SQ is a tool aimed at this purpose and, in Portugal, a 63.9% sensitivity and 67.3% specificity, and positive and negative predictive values of 29.9% and 89.5%, respectively, have been found.¹² Given the prevalence of palliative needs, there seems to be room for improvement in this identification.

Specificity was not assessed in the analysis of responses to both tools, preventing from reaching any conclusions on whether the combined use of both tools would lead to an increase in false positives. Nevertheless, we found in this specific population that not only does NQ have greater sensitivity than SQ in all calculations, but the sensitivity value of the former is always increased when it is combined with the latter. In this regard, the comparison of sensitivity values of other tools used to identify patients with palliative needs would be relevant: five instruments (SPICT, SQ, NECPAL, eFI and the Rainoe tool for the early identification of patients with palliative needs) were analysed in a recent systematic review and great variability in sensitivity values, between 3.2% and 94%, were found.¹⁹ More specifically, the SQ identified between 1.6% and 79% of patients with palliative needs and in the studies in which this tool was applied to patients with advanced disease, it was able to identify between 41% and 79% of patients with palliative needs¹⁹; a 73% average SQ sensitivity has been found in another

systematic review.²⁰ In this study, for both populations, a sensitivity within this range of values has been found, even though below the average (48.2% for SQ alone); in addition, the sensitivity of NQ was also in line with these values (58.9% alone). When used together, the sensitivity of both tools has increased 16% when compared to the use of SQ alone and around 5% compared to NQ (64.2% sensitivity of SQ with NQ).

As regards patients with neoplasms, a lower sensitivity in identifying patients with palliative needs has been found (33.3%), which increased by around 22% when NQ was added. Whenever the NQ was used alone, a similar sensitivity to the one obtained when using both tools combined has been found, identifying half of the patients with PPCN due to neoplasm (50.0% sensitivity). However, the new tool seems most useful in the identification of patients with dementia; in these cases, the addition of SQ did not translate into an increase in sensitivity over the use of NQ alone. In fact, the tool created for this study was able to identify more than nine out of 10 patients with dementia and palliative needs (92.3% sensitivity). A 69.2% sensitivity has been found with the use of the SQ. This means that, in this condition, due to its insidious progression, waiting for the SQ to become positive can lead to a delay in the implementation of palliative care and a subsequent deterioration in the condition of these patients.

A 2.1% prevalence of advanced disease has been found in our group of patients, close to the 1.5% prevalence described in literature for the general population,¹⁶ reinforcing the relevance of the early identification of these patients and strengthening the involvement of primary care in this treatment modality.

A percentage of 45.3% of the patients in our study presented with dementia as an active problem, at an advanced stage of their disease. There are few international estimates of the prevalence of advanced dementia. Nevertheless, knowing that this pathology is still underdiagnosed,^{21,22} it seems legitimate to infer that the cases identified are already moderate and severe forms of the disease, which may overestimate the prevalence of advanced disease. Despite this potential bias, it seems clear that there is a need

for greater identification of this problem in clinical files, enabling an early action in the earlier stages of the disease,²³ but also the implementation of palliative actions consistently in the more advanced stages, with a higher prevalence of these needs.

In this study, we also found data on the prevalence of neoplasm, which is partially in line with the available estimates. In fact, a recent systematic review has found the presence of neoplasm of the female breast, lung, prostate, colon and stomach as the most prevalent worldwide.²⁴ Compared to the results obtained in the study, the low prevalence of lung and bronchial cancer in our group of patients stands out, with only 2.0% of all cases, as well as the high prevalence of malignant skin neoplasm, accounting for 5.5% of all coded neoplasms. The high social impact of neoplasms reinforces the relevance of the proximity of physicians to the community in which they work and of which they are an active member.¹³ In fact, these professionals have a wide-ranging role, providing support in personal, work and social matters.¹³ In line with this, a study has shown that both physicians, nurses and the patients themselves describe that the main responsibilities of these professionals are not only relieving physical symptoms, but also providing psychological and existential support to patients with advanced neoplasm.²⁵

The analysis of data on advanced dementia showed a higher prevalence of this stage in females, with 69.0% of all cases. This relationship is in line with different studies on the subject^{26,27} and, although the cause is still unknown, it is thought to be due to longer life expectancy of female patients - according to the National Statistics Institute, Portuguese female patients live on average around five years longer than male patients.²⁸

Since ageing is the main risk factor for developing dementia,^{29,30} the results in our study regarding age are not surprising: the average age of patients with dementia is 83.3 years and the youngest patient is 71 years old. Ageing is also associated with an increased burden of disease^{2,31} and, therefore, an increased need for palliative care.³¹

The lack of data on the patients' education was found in both subpopulations. In fact, education is crucial to the adequacy of the delivered information and communication between doctors and patients. Inadequate communication increases the likelihood of patients not adhering to treatment, reduces their satisfaction and, ultimately, leads to an inadequate use of healthcare resources.³²

The same problem has also been found regarding patients' income. Despite this, the present data allows reach-

ing some conclusions: almost 25% of dementia patients and around 15% of neoplasm patients were ranked as SEDI 1 (24.1% and 15.4%, respectively). Given the specific needs of our group of patients, low income may be a constraint to obtaining appropriate healthcare. A systematic review has shown that some of the constraints in providing palliative care to patients with low income include suboptimal infrastructure, lack of access to drugs for symptomatic relief and the absence of a structured palliative care network.³³ In addition, low income contributes to an increased burden of disease.³⁴

Multimorbidity can be defined as any combination of chronic diseases and another disease (acute or chronic) or another biopsychosocial factor or a somatic risk factor³⁵ and is present in any age group, although it is more prevalent in the elderly.³⁶ This is a significant health problem translating into a poorer quality of life.^{36,37}

Polypharmacotherapy (also associated with multimorbidity) has also been found in our study.³⁸ This can be defined as the use of five or more drugs on a chronic basis and a 45% prevalence has been found in patients aged 65+, unrelated to factors such as gender or geographical location.³⁹ The use of an average of 6.8 drugs has been found, as chronic medication in patients with advanced neoplasm and 7.5 in those with advanced dementia. For this reason, deprescribing should be considered and should be seen as a therapeutic intervention like introducing a new medication.⁴⁰ The removal of unnecessary drugs reduces pill burden, the risk of adverse effects and the financial impact on patients.⁴⁰ Given the interdependence of these two concepts, the proximity of primary care and their holistic approach are essential.

As regards healthcare, we found that patients with advanced dementia are assessed, on average, around once a quarter (3.8 medical appointments per year) in primary care and just over once a year in secondary care (1.5 appointments per year). This reflects an enlightening reality: in fact, primary care is the main point of contact with these patients.¹³ Most patients wish to remain at home through the final stage of their lives, as described by the WHO,¹⁴ where the role of primary care is crucial: home visits are carried out and primary care units are generally more easily accessible than secondary care. Nevertheless, the same organisation reinforces the need for integration between primary and secondary care if a patient must be transferred to a secondary care institution due to refractory symptoms.¹⁴ Training in palliative care is crucial to ensure the best possible preparation for dealing with these patients. A study

carried out in Portugal has shown that, even though family doctors felt able to look after patients with PPCN, the implementation of training in this type of care is crucial, in addition to the integration of primary care into a national palliative care network.⁴¹ Another author also reinforced the need for training in palliative care for family doctors.⁴²

On the other hand, patients with advanced neoplasms more frequently attend secondary than primary care: our results have shown that these patients attended, on average, more than one primary care consultation every two months (an average of 7.4 consultations per year) and attended medical appointments in secondary care almost monthly (10.0 per year, on average). For this very reason, the impact of these patients on the National Health System must be considered. There is still little consensus on the health costs of patients with PPCN: some studies⁴³⁻⁴⁵ have shown that early access to palliative care translates into lower health costs within the final year of life - by reducing admissions to hospital- although other studies have shown no significant differences between providing palliative care in hospital or at home.^{46,47} This should be considered more carefully to ensure an widespread access to palliative care.

Still, the study has some limitations, considering the use of a non-representative group of patients, in addition to a convenience sample of family physicians. There was also a lack of information, particularly regarding education and income. Patient selection was based on clinical records, which are not error-free.⁴⁸ The fact that only sensitivity was calculated prevented from assessing the number of false positives. In addition, there are no clear criteria for the definition of advanced dementia, which may have had an impact on the results. Finally, benign neoplasms and those of uncertain nature or with unknown behaviour were included in the study, so as not to miss any diagnosis of neoplasm. This may have led to an underestimation of the prevalence of advanced neoplasms in our group of patients.

Even so, the study has ensured the characterisation of two populations of patients with advanced disease in terms of multiple criteria, both clinical and sociodemographic, and a possible tool for the identification of patients with PPCN was analysed, with particularly promising results among the population diagnosed with dementia.

Further studies on the use of this tool with a representative sample of participants and calculating specificity are crucial. Combining the SQ with a new tool could improve the timely identification of patients with PPCN.

CONCLUSION

This study has allowed the characterisation of two populations of patients with advanced disease and a 2.1% prevalence was found in primary care. The use of NQ in the identification of advanced dementia proved to be a tool with greater potential than the SQ (92.3% and 69.2% sensitivity, respectively). An instrument combining both questions could be considered, as the combined use of both tools led to an increase in sensitivity of patient identification, identifying 64.2% of patients with potential palliative care needs, 55.6% of patients with advanced neoplasms and 92.3% of patients with advanced dementia.

AUTHOR CONTRIBUTION

LP: Data collection and treatment, writing of the manuscript.

IR: Methodology, review and edition of the manuscript.

CSC: Methodology, data treatment, review and edition of the manuscript.

The present version of the manuscript was approved by all the authors.

HUMAN AND ANIMAL PROTECTION

The authors declare that this project complied with the regulations that were established by the Ethics and Clinical Research Committee, according to the 2013 update of the Helsinki Declaration of the World Medical Association.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

CONFLICTS OF INTEREST

IR has received consultancy fees from Novo Nordisk; payment or honoraria for lectures, presentations, conferences, manuscript writing or educational events from Boehringer Ingelheim, Astra Zeneca and MSD; support for attendance at meetings and/or travel from MSD, Ferrer Portugal, and Novo Nordisk.

The authors declare that they have no conflicts of interest related to this work.

FINANCIAL SUPPORT

The authors declare that there was no financial support in writing this manuscript.

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