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# Unmet needs of ambulatory cancer patients undergoing cancer treatments in a Portuguese hospital: a cross-sectional study

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## Abstract

**Background** Patients with cancer experience a variety of needs at every stage of their illness. Many of these needs can be addressed with palliative care. Cancer patients' palliative needs should therefore be proactively identified and managed. This study aimed to identify the needs of oncology patients receiving out-patient cancer treatment at a Portuguese cancer center.

**Methods** A cross-sectional study was undertaken of consecutive patients presenting to an outpatient cancer clinic over the course of 5 days for cancer treatments. The primary outcome measure was the validated Portuguese version of the Integrated Palliative Care Outcome Scale (IPOS). "Unmet needs" were defined as symptoms/needs rated as greater than 2 out of 4.

**Results** Of 211 patients registered for clinic visits, 167 were potentially eligible and 113 (67.7%) completed the questionnaire. Cancers of the breast (31%), colorectum (18%), and lung (14%) were the most common, and 52% were stage IV cancers. Functional levels as assessed by the Eastern Cooperative Oncology Group (ECOG) were 31.8% (ECOG 1), 54.9% (ECOG 1) and 12.4% (ECOG 2). Almost all patients (99%) reported at least one symptom or need regardless of severity; 76%, 57% and 16% reported at least one, two to four, and five or more severe symptoms/needs, respectively. The most frequently reported physical "unmet" symptoms were pain (12%), poor mobility (12%) and weakness (11%). The psychological and social needs included anxiety (18%), depression (11%), difficulty sharing feelings (25%), information needs (23%), and family concerns (47%). The prevalence of unmet needs increased notably if moderate-intensity needs (2 out of 4) were included as "unmet" needs. Female sex and higher ECOG scores were associated with higher (worse) IPOS scores.

**Conclusions** A high burden of unmet needs was identified among ambulatory cancer patients at this center, particularly among female patients and patients with poorer ECOG. Quality improvement initiatives are needed to

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improve the systematic screening of patient needs and integrate a palliative care approach earlier to help address them.

**Keywords** Palliative care, Neoplasms, Cancer treatment, Quality of life, Outcome assessment, Cancer care facilities

## Introduction

Cancer remains a leading cause of morbidity and mortality globally [1]. In Portugal, it is responsible for one in every four deaths, with incidence rates expected to increase as the population grows and ages [2, 3]. This trend places significant demands on healthcare resources, but its most profound effect is on the quality of life of those affected and their families.

Patients living with cancer – whether curable or incurable – experience significant needs across several areas, including the physical, psychological, spiritual, and informational domains [4–9]. These problems and needs, which occur at every stage of the illness, may significantly affect quality of life and may be caused by the cancer itself, cancer treatments, preexisting or concurrent conditions, and from suboptimal communication and support by healthcare providers and other care providers [10].

Palliative needs should be actively assessed by healthcare professionals who provide care to cancer patients. However, studies continue to demonstrate that these needs are often unidentified and unaddressed, leading to a reduced quality of life of patients and poor resource utilization [11, 12]. Simply asking patients how they feel is insufficient to elicit patient needs [13]. Standardized questionnaires are important tools for assessing patients' needs, offering structured opportunities for symptom reporting and systematic inquiry. The median number of symptoms identified through systematic assessment can be up to ten times higher than that reported by patients via open-ended questioning [14]. Additionally, standardized questionnaires may facilitate the initiation of difficult conversations and help address concerns that patients might not spontaneously disclose [15].

The evidence indicates that the regular and systematic use of patient-reported outcome measures (PROMs) in daily practice, including instruments and scales for screening and evaluating symptoms and other needs, offers numerous benefits. These include improvements in symptom management, quality of life, survival rates, patient satisfaction, patient–doctor communication, and health resource utilization [16–20]. Consequently, there are increasing calls to integrate PROMs into routine practice, supported by large-scale, system-wide implementations [21, 22].

This study aimed to identify the palliative care needs of oncology patients undergoing cancer treatment at a regional cancer center in southern Portugal, intending

to inform future quality improvement initiatives at the center.

## Methods

### Design and setting

An observational cross-sectional study was undertaken of patients receiving medical oncology outpatient care at the public Faro University Hospital in Algarve, Portugal.

### Participants

The inclusion criteria included 18 years or older, a cancer diagnosis, undergoing systemic cancer treatments (chemotherapy, endocrine therapy, immunotherapy, or other targeted therapy), and the ability to read and write Portuguese. Patients who exclusively received radiotherapy or surgery, patients undergoing cancer diagnostic and staging investigations, and patients in remission undergoing cancer surveillance were excluded.

Due to resource constraints, recruitment was limited to one week (five working days) in April 2023. A research team member was given access to the daily patient list and reviewed patient charts to determine eligibility. Participants were recruited voluntarily and provided written consent.

### Data collection and analysis

The primary outcome measure was the validated Portuguese version of the Integrated Palliative Care Outcome Scale (IPOS), the IPOSv1-P7-PT [23, 24]. The IPOS is a validated instrument used to screen for and assess patient needs across several domains including physical symptoms, psychological well-being, social functioning, and information needs (see **Appendix A**). There are 10 questions, most of which are scored on a scale of 0 to 4, with 0 indicating absence of a problem and 4 representing the highest level of severity or need. The theoretical maximum total score is 80. The first question asks patients to describe, using text, up to three main problems or needs they have experienced over the previous week. Patients may also add additional symptoms not listed amongst ten standard ones. The spiritual domain is largely represented by a single item that explores the patient's sense of feeling at peace. The IPOS is completed by patients (themselves or with the assistance of a family member, friend or staff member). The tool helps healthcare providers identify areas of need and monitor changes over time, guiding individualized care plans to improve patients' overall comfort and quality of life.

Additional data collected included participant demographic information (age, self-declared sex, and marital status), performance status using the Eastern Cooperative Oncology Group (ECOG) scale, primary tumor type, and cancer stage, according to the Eighth Edition of the American Joint Committee on Cancer (AJCC) staging manual. The ECOG score represents a patient's functional status; a higher ECOG score corresponds to a lower functional level (0 represents no restrictions on activities and 4 total disability).

Descriptive statistics were used to report demographic information, and presence, severity, and distribution of symptoms and needs. To further explore the extent of unmet needs in each domain, 'unmet' needs were defined a priori as symptoms and needs rated greater than 2 on the IPOS scales. A subgroup analysis was conducted to investigate associations between independent variables (age, sex, marital status, cancer stage, and ECOG performance status) and the dependent variable (total IPOS score for each patient). Inferential statistical tests included Student's *t* test (total IPOS score with sex), Pearson correlation (total IPOS score with age), and ANOVA (total IPOS score with marital status, ECOG score, and cancer stage). The Statistical Package for the Social Sciences (SPSS), version 26.0, was used for analyses.

### Ethics

The study was reviewed and approved by the Research Ethics Board (REB) of the Faro University Hospital in September 2022 (study number 186/22).

### Results

Of the 211 patients scheduled for cancer treatments during the recruitment week, 29 did not meet the inclusion criteria, and 15 missed their appointments. Out of the 167 patients approached, 38 declined to participate, and 16 did not complete the questionnaire, resulting in 113 completed questionnaires (response rate 68%) (see Fig. 1). The participant demographics are summarized in Table 1. The most prevalent malignancies were breast cancer (31%), colorectal cancer (18%), and lung cancer (14%). Some malignancies were represented by only one or two participants. With respect to cancer stage, 24% of patients had stage III cancer, and 52% had stage IV cancer. Functional levels, as assessed by the Eastern Cooperative Oncology Group (ECOG), were relatively high; 31.8%, 54.9%, and 12.4% had ECOG levels 0, 1 and 2 respectively.

Almost all patients (99%) reported the presence of at least one symptom or problem, regardless of its severity. A total of 86 patients (76%) reported at least one severe need (rated 3 or 4). Among these, 49 patients (57%) reported 2 to 4 severe needs (rated > 2), and 14 patients (16%) reported 5 or more severe needs (rated > 2). The

overall mean IPOS score was 18 (SD = 9), with a median of 17 and a range of 0 to 43.

The number of participants who reported each symptom/need and their severity are presented in Fig. 2. The most frequently reported physical symptoms, regardless of severity, were (number of participants followed by percentages) weakness (84;74%), pain (62;54%), and sore/dry mouth (59;52%). The most frequently reported high-intensity symptoms (rated > 2) were pain (13;12%), poor mobility (13;12%), and weakness (12, 11%).

For psychological needs, 94 (83%) of the participants self-reported feelings of anxiety or worry about their illnesses or treatments over the previous week, and 20 (18%) rated their anxiety as severe (> 2). Regarding depression, 64 patients (57%) reported feeling depressed, and 12 (11%) rated their depression as severe (> 2). Sixty patients (53%) reported information needs, and 26 (23%) of these patients rated these needs as significant (rated > 2), whereas 53 (47%) and 28 (25%) reported significant family concerns and difficulties sharing their feelings, respectively. Twelve (11%) of all the respondents reported a severe lack of sense of peace (rated > 2) (see Fig. 2).

If, for all the physical, psychological, social, and practical needs, ratings of 2 on the scale were included as "unmet" needs, the prevalence of these needs would rise substantially for several symptoms and needs. In the case of pain, for example, unmet needs were present in 32 patients (28%), 36 (32%) for weakness, 25 (22%) for poor appetite, and 24 (21%) for constipation. Similarly, for psychological and social needs: 73 (65%) anxiety, 43 (38%) depression, feelings of lack of peace 35 (31%), difficulties sharing feelings 47 (42%), family concerns 84 (74%), and information needs 37 (33%).

Fifty-three (47%) participants responded to the open-ended question that asked them what the main problems or concerns were that they had experienced the previous week. The most commonly reported ones were pain ( $n=8$ ) and concerns about family or friends ( $n=11$ ), treatment-related toxicities ( $n=7$ ), loss of independence ( $n=6$ ), work or finances ( $n=5$ ), disease recurrence or progression ( $n=5$ ), the future ( $n=4$ ), delays in treatments ( $n=2$ ) and lack of appetite ( $n=2$ ). Other included anxiety ( $n=3$ ) and fear of death ( $n=2$ ).

Twenty-five participants (22%) described additional symptoms not listed in the IPOS. The most common were neuropathy ( $n=6$ ), diarrhea ( $n=3$ ), impaired vision ( $n=3$ ), dizziness ( $n=3$ ), skin changes ( $n=3$ ), concentration and memory loss ( $n=3$ ) and bleeding ( $n=2$ ).

Only 2 of the 5 subgroups analyzed were associated with higher IPOS scores, namely, ECOG performance status and female sex (see Table 2). A higher ECOG score correlated with higher IPOS scores ( $r_s=0.261$ ,  $p=0.018$ ), and females tended to score higher on the questionnaire

than males ( $p=0.004$ ). No significant correlation was found between the IPOS score and other variables (age, marital status, or cancer stage).

## Discussion

In this study, a large proportion (99%) of ambulatory patients followed at an outpatient cancer clinic reported having symptoms and needs across several domains. 76% of patients reported at least one symptom or need that was rated as *severe to very severe* or *very frequent to all the time*. The most reported physical symptoms rated as high were pain (12%), poor mobility (12%), and weakness (11%), and 18% of patients reported high to very high emotional needs and information needs (23% of respondents). This represents a high burden of needs across physical, psychological, social, and information domains among study participants and opportunities to improve their quality of life.

Female sex and poorer ECOG performance status were associated with higher scores on the IPOS questionnaire, which is consistent with many previous studies [25–29]. Several reasons may explain why women have higher IPOS scores than men do. Breast cancer was the most prevalent cancer in our study, affecting only women. Endocrine therapy is frequently prescribed for hormone-dependent breast cancer. It can elicit several side effects, such as sleep disturbance, depression, anxiety, bone loss, joint and connective tissue discomfort, genitourinary syndrome of menopause, and sexual dysfunction [30]. Men can experience side effects similar to those of endocrine therapy for prostate cancer [31]. However, few patients with prostate cancer were included in our study.

Patients with higher ECOG scores had higher, and consequently worse, IPOS scores. Functional status includes basic activities of daily living (bathing, dressing, toileting, feeding, transferring), instrumental or intermediate activities of daily living (grocery shopping, preparing meals, managing finances, driving, housework, taking medications, etc.), and advanced activities of daily living (recreational or occupational activities and social or family roles) [15]. Higher ECOG scores may be both a cause and a consequence of unmet needs. Functional limitations can cause uncontrolled symptoms, especially in the psychological and emotional domains. Conversely, difficulties with self-care and the inability to perform household chores may result from uncontrolled symptoms, particularly in the physical domain. Rehabilitation should be an essential component of a cancer patient's treatment plan since it supports them in being as independent as possible, giving them the autonomy to accomplish desired tasks and live a meaningful life [32, 33].

The high burden of symptoms and needs reported in our study is similar to that reported in many previous studies [26, 34–41]. These findings demonstrate that

these needs are often unidentified and unaddressed, leading to a reduced quality of life of patients and poor resource utilization [6, 13]. Patients may be reluctant to disclose their symptoms to healthcare providers to avoid being perceived as “bad patients” or because of misperceptions that these symptoms are not amenable to treatment or fear of those treatments [42]. On the other hand, healthcare professionals may avoid asking about them because they might lack the skills or resources to address them or because of time constraints, since soliciting them may add additional workload [43, 44].

The use of PROMS in everyday practice helps address some of these barriers and improve patient care. Numerous validated instruments and standardized approaches have been described and used in cancer care [45–48]. Among the most commonly used scales, in addition to the Integrated Palliative Care Outcome Scale (IPOS), are the Edmonton Symptom Assessment System (ESAS), the Palliative Care Outcome Scale (POS), and the Distress Thermometer/Problem Checklist. They each have their respective strengths and limitations, depending on the goals and context of use. The simplicity and ease of application are essential for daily use.

In our study, patients reported high levels of burden in the psychological and spiritual domains (we linked, in our analysis, “sense of peace” to the spiritual domain, recognizing the multidimensionality of that construct). Others have previously reported similar findings of high needs in the psychological and informational domains, sometimes even higher than those in the physical domain [12, 37, 49–51]. Several reasons may account for this. The management of physical symptoms can be performed with pharmacological therapies. In Portugal, for example, there may be easier access to pharmacological modalities to manage symptoms such as antiemetics, which can be provided free of charge at medical oncology units. Other medicines, such as opioids, are available at a lower cost to cancer patients in community pharmacies, according to Portuguese legislation. Similarly, there are cheaper generic versions of essential supportive medicines, and even if patients cannot afford them, some national cancer organizations may provide financial assistance to purchase them.

Dealing with psychological symptoms requires soft skills and access to mental health providers, which could be lacking in some institutions [52, 53]. Living with cancer can also lead to feelings of shame, blame, and guilt, which can be barriers to seeking professional help. Psychological and spiritual needs are associated with poorer treatment outcomes, diminished decision-making capacity, prolonged hospitalization, and suicide [15]. Spirituality plays an important role in the setting of serious illnesses [54]. Studies support the standard integration of

spiritual care into medical care, which can improve quality of life [55, 56].

Information needs were the highest needs identified by patients in our study. Cultural factors may explain some of this [57]. Health literacy levels differ substantially across countries [58]. In Portugal, younger patients (up to the age of 45 years) have better health literacy than older patients do [58, 59]. Earlier studies in Portugal, for example, reported that clinicians may often be reluctant to disclose information because they fear that it removes hope or elicits emotional responses in patients [60, 61]. Studies also suggest that clinicians do not spend enough time discussing test results and prognostic implications, leading patients to overestimate their probability of long-term survival and creating a false sense of optimism [62, 63].

Patients may also contribute to information sharing barriers, including discussing prognosis [64, 65]. In poor prognosis situations, they may not ask for information or may not absorb it even when it is provided [65]. However, during the last decade, a cultural shift has occurred in Portugal in this area, among healthcare professionals and the public, recognizing the need for more information sharing and disclosure [66].

Nonetheless, as our study shows, ongoing needs related to information persist and need to be addressed. Multiple strategies that include increased advocacy, public education and mobilization, communication training, and continuing professional development in the supportive and palliative care of healthcare professionals are needed and have been shown to be successful [62, 67].

The study results raise an important question: who is responsible for assessing patient symptoms and needs and responding to them? Increasingly, experts across the world are recognizing that while adequate specialist palliative care services are needed, including interprofessional teams, it is neither feasible nor appropriate to rely only on specialist palliative care services to provide for all the supportive and palliative care needs of a population. Specialist palliative care teams combine advanced training and experience in palliative care and are especially available for patients with complex needs across various settings (including inpatient and outpatient hospital settings and in the community) [68, 69].

### Limitations

Several limitations are acknowledged. Our focus was on the unmet needs of cancer patients receiving disease-modifying cancer treatments (with curative or palliative intent). The needs of patients in our institution who are no longer receiving such treatments or who are cancer survivors may differ. Overall, the sample size was small relative to all the patients cared for at our institution. Some cancers are not well represented, and the needs of patients with those cancers may differ. Nonetheless, we

believe that the sample size is sufficient to inform quality improvements in this area. A limitation of IPOS is that it does not explore different types of social needs and spiritual needs in more detail and misses other needs, such as those related to functioning and sexuality [70]. Finally, the Algarve region is increasingly home to a large expatriate population from other parts of Europe and internationally, with many residents who have little or no proficiency in Portuguese.

### Conclusion

In this study of ambulatory cancer patients presenting to a cancer clinic in Portugal for outpatient cancer treatment, a high burden of symptoms and unmet needs was identified. Almost all participants reported at least one symptom, and over half of participants reported experiencing two to four severe symptoms or needs. The most frequently reported physical “unmet” symptoms were pain, poor mobility and weakness, while anxiety, depression and difficulty sharing feelings were the most frequently reported “unmet” psychological needs. Just over half of participants were experiencing information needs and almost one in two patients reported family concerns. Female sex and poorer functional levels were associated with higher levels of unmet needs.

The high levels of symptoms and needs, many unaddressed, calls for quality improvement initiatives at the centre to ensure patients’ needs are identified and addressed. These should include the systematic use of patient reported outcome measures to screen for and monitor patient needs, increased integration of the palliative care approach in the cancer centre to equip cancer teams with skills to address these needs and to collaborate with the palliative care service, and importantly, initiatives to better address the information needs and health literacy of patients.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-025-01766-7>.

Supplementary Material 1

### Author contributions

All the authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by FS, JLP and MLC. The first draft of the manuscript was written by FS, AF and JLP, and all the authors commented on previous versions. All the authors read and approved the final manuscript.

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### Data availability

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon reasonable request.

## Declarations

### Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Faro University Hospital (September 2022/No. 186/22).

### Consent to participate

Informed consent was obtained from all individual participants included in the study.

### Consent for publication

Informed consent was obtained from all individual participants included in the study.

### Competing interests

The authors declare no competing interests.

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