

## Referral Delays to Specialized Palliative Care among Oncology Inpatients in a Portuguese Cancer Centre

### Atrasos na Referenciação para Cuidados Paliativos Especializados em Doentes Oncológicos Internados num Centro Oncológico Português

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#### ABSTRACT

Access to specialized palliative care is a key component of quality cancer care, yet delays remain common in Portugal and institution-level data on referral pathways are scarce. We performed a retrospective observational study including all oncology inpatients referred to specialized palliative care units at a Portuguese comprehensive cancer center between January 2022 and June 2024, and we analysed referral outcomes and waiting times from referral to admission or death. Of 3177 hospitalized oncology patients, 208 (6.5%) were referred to palliative care, and nearly two-thirds (63.0%) died before admission. The median waiting time from referral to admission was 29.5 days (IQR 20.0 – 41.0), while patients who were not admitted died a median of 34.0 days (IQR 20.0 – 54.0) after referral. Among admitted patients, median length of stay in palliative care units was 21.5 days (IQR 10.0 – 40.5). These findings show that most hospitalized oncology patients referred to specialized palliative care do not reach admission in time, reflecting substantial delays in access despite referral. Improving referral pathways and strengthening system capacity are essential to ensure timely palliative care for patients with advanced cancer in Portugal.

**Keywords:** Neoplasms; Palliative Care; Portugal; Referral and Consultation; Waiting Lists

#### RESUMO

Embora o acesso a cuidados paliativos especializados seja um componente fundamental dos cuidados de qualidade em Oncologia, os atrasos no acesso permanecem frequentes em Portugal e os dados institucionais sobre os circuitos de referenciação são escassos. Realizámos um estudo observacional retrospectivo incluindo todos os doentes oncológicos internados referenciados para unidades de cuidados paliativos especializadas num centro oncológico português, entre janeiro de 2022 e junho de 2024, e analisámos os desfechos da referenciação e os tempos de espera desde a referenciação até à admissão ou óbito. Dos 3177 doentes oncológicos internados, 208 (6,5%) foram referenciados para cuidados paliativos, tendo cerca de dois terços (63,0%) falecido antes da admissão. O tempo mediano desde a referenciação até à admissão foi de 29,5 dias (IQR 20,0 – 41,0), enquanto os doentes não admitidos faleceram ao fim de uma mediana de 34,0 dias (IQR 20,0 – 54,0) após a referenciação. Entre os doentes admitidos, o tempo mediano de internamento em unidades de cuidados paliativos foi de 21,5 dias (IQR 10,0 – 40,5). Estes resultados sugerem que a maioria dos doentes oncológicos internados referenciados para cuidados paliativos especializados não é admitida atempadamente, o que reflete atrasos relevantes no acesso, apesar da referenciação. A otimização dos circuitos de referenciação e o reforço da capacidade do sistema são essenciais para garantir o acesso atempado a cuidados paliativos em doentes com doença oncológica avançada em Portugal.

**Palavras-chave:** Cuidados Paliativos; Encaminhamento e Consulta; Listas de Espera; Neoplasias; Portugal

Cancer remains a major cause of morbidity and mortality worldwide and in Portugal. Although advances in oncological treatments have improved survival, many patients still experience advanced disease associated with high symptom burden, reduced quality of life, and complex care needs.<sup>1,2</sup> In this context, timely access to specialized palliative care is essential to ensure adequate symptom control, appropriate end-of-life care, and support for patients and families.<sup>3,4</sup>

The evidence consistently shows that early integration of palliative care within oncology pathways improves patient-reported outcomes and healthcare use. However, in clinical practice, access to specialized palliative care remains limited by late referral, complex referral pathways, and insufficient system capacity.<sup>5</sup> These barriers are particularly relevant for hospitalized oncology patients, who often represent a population with advanced disease and urgent palliative needs.<sup>6,7</sup>

In Portugal, despite the progressive development of the national palliative care network, substantial waiting times for admission to specialized palliative care units persist, and a significant proportion of referred patients die before admission.<sup>8</sup> Institution-level data describing referral patterns and delays in this setting are scarce, limiting the ability to identify specific bottlenecks and target improvement strategies.<sup>9</sup>

The aim of this study was to characterize referral patterns from an oncology inpatient unit to specialized palliative care units (PCU) and to quantify waiting times and outcomes following referral in a Portuguese cancer centre.

We conducted a retrospective observational study including all adult ( $\geq 18$  years) oncology inpatients referred to specialized PCU between January 2022 and June 2024 at the Medical Oncology inpatient unit of Instituto Português de

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Oncologia de Lisboa Francisco Gentil (IPOLFG). All hospitalized oncology patients were screened. Patients were identified through retrospective review of electronic medical records, complemented by consultation of the institutional referral platform to the national palliative care network, allowing identification of referrals to both public and private PCU. No patients were excluded due to missing data.

Demographic and clinical variables collected included age, sex, tumour type, referral date, date of assessment by the hospital palliative care team, date of registration on the national palliative care platform, and referral outcome (admission to a palliative care unit or death before admission). For patients admitted to a PCU, the date of admission and date of death were recorded. Patients who were alive at the end of the observation period were censored.

Waiting time was defined as the number of days between referral and either admission to a PCU or death. Additional time intervals along the referral pathway were analysed, including hospital admission to palliative care team assessment, assessment to registry entry, and registry entry to final outcome. Length of stay in the PCU was calculated from admission to death.

Descriptive statistics were used to summarize the data. Categorical variables were reported as absolute frequencies and percentages, and continuous variables as medians with interquartile ranges. Comparisons between groups were performed using non-parametric tests when appropriate, with a significance level of  $p < 0.05$ . Statistical analyses were performed using SPSS version 30.0.

The study was approved by the IPOLFG Ethics Committee (UIC/1790), and the requirement for informed consent was waived due to the retrospective and anonymized nature of the analysis.

From January 2022 to June 2024, 3177 oncology patients were hospitalized, of whom 208 (6.5%) were referred to a specialized PCU. Patient characteristics, referral outcomes and waiting times are summarized in Table 1.

The median age of referred patients was 70 years (IQR 62 – 78), and 64.9% were women. The most frequent tumor groups were head and neck, breast, gastrointestinal, and gynecological cancers.

Of the 208 referred patients, 77 (37.0%) were admitted to a PCU, while 131 (63.0%) died before admission. Three admitted patients were alive at the end of follow-up and were therefore censored. Median waiting time from referral to admission was 29.5 days (IQR 20.0 – 41.0). Among patients who died before admission, median time from referral to death was 34.0 days (IQR 20.0 – 54.0). Median length of stay in PCU was 21.5 days (IQR 10.0 – 40.5), with 96.1% of admitted patients dying during their stay.

Analysis of the referral pathway revealed delays at multiple stages, including the interval between hospital admission and evaluation by the in-hospital palliative care team, which is responsible for referral to specialized PCU, the administrative progression to registry entry, and the waiting period after registration (Fig. 1). For admitted patients, the median time from hospital admission to evaluation by the in-hospital palliative care team was 3 days (IQR 2.0 – 5.0), followed by 8.5 days (IQR 6.0 – 16.5) from evaluation to registry entry, and 29.5 days (IQR 20.0 – 41.0) from registry entry to admission. Overall, the longest delay occurred after registry entry, and similar patterns were observed among patients who died before admission.

Referral-to-outcome time differed significantly by tumor type, whereas no significant differences were observed according to age or sex. Given the exploratory nature of these comparisons and small subgroup sizes, no further stratified analyses were performed.

This study showed that most oncology inpatients referred to specialized PCU died before admission, with waiting times exceeding one month from referral. These findings highlight substantial delays within the referral pathway, even in a comprehensive cancer centre with an established in-hospital palliative care team.

Delays were observed at multiple stages of the referral process, including the interval between hospital admission and palliative care assessment, the administrative progression to registry entry, and the waiting period after registration. Notably, the longest delay occurred after registry entry, suggesting that limited system capacity and bed availability may play an important role in restricting timely access to specialized palliative care. This pattern is consistent with national data reporting high proportions of patients dying while on waiting lists.<sup>8,9</sup>

Referral-to-outcome time differed according to tumor type (more delay in gynaecologic cancers, less delay in skin cancers), whereas no significant differences were observed by age or sex. While previous studies have explored factors influencing access to palliative care, there is limited and inconsistent evidence that specifically addresses the impact of tumor type on referral timing and access to PCU. In this context, our findings suggest that disease-related factors may play a role in referral patterns, although this observation warrants further investigation.

Several factors were identified during clinical practice that may have contributed to delayed or unsuccessful admission to specialized PCU. These included limited unit capacity and prolonged waiting lists, as well as complex family

decision-making processes and patient reluctance to accept referral. Such observations were not systematically collected and should therefore be interpreted cautiously. Nevertheless, they highlight potential areas for improvement in communication, referral coordination, and patient and family engagement during hospitalization. A relevant organizational change during the study period was the termination, in 2022, of a collaboration with an intermediate care facility that had previously assisted during patient transitions. Although its impact was not formally quantified, the absence of this intermediate-care pathway may have contributed to increased pressure on existing PCU and longer waiting times.

The high mortality rate observed shortly after admission to a PCU further supports the notion of delayed referral, with median lengths of stay of just over three weeks. Such late transitions limit the potential benefits of specialized palliative care and may contribute to prolonged and potentially avoidable hospitalizations in acute care settings.

This study has limitations inherent to its retrospective design, including the absence of detailed clinical severity indicators (e.g. performance status or metastatic burden), and incomplete follow-up data from external PCU. Additionally, the descriptive nature of the analysis, the use of aggregated time intervals, and the limited sample size for subgroup analyses did not allow for more detailed comparisons and adjustment for potential confounders. However, its strength lies in the comprehensive evaluation of the referral pathway and the use of real-world institutional data, which allows the identification of specific delays amenable to targeted interventions.

In conclusion, substantial delays persist in the referral of oncology inpatients to specialized PCU, with most patients dying before admission. These findings highlight the need to optimize referral and strengthen system capacity, while reinforcing the importance of earlier integration of palliative care in clinical practice. They also support the need for broader efforts to improve awareness and understanding of palliative care among patients and families, helping to reduce stigma and facilitate timely referral. Future research should focus on identifying determinants of delayed referral and evaluating interventions to improve timely access in this setting.

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The authors declare that no AI tools were used during the preparation of this work.

## AUTHOR CONTRIBUTIONS

PAM: Study conception and design, data collection, statistical analysis, drafting of the manuscript.

IV, BP, CP, SM: Data collection, critical review of the manuscript.

CC, MF, CR, FV: Critical review of the manuscript.

All authors approved the final version to be published.

## PROTECTION OF HUMANS AND ANIMALS

The author declares that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in October 2024.

## ETHICS

This study was approved by the Ethics Committee of Instituto Português de Oncologia de Lisboa Francisco Gentil (reference number: UIC/1790).

## DATA CONFIDENTIALITY

The authors declare that they followed the protocols in use at their working center regarding patients' data publication. The datasets generated and/or analysed during the current study are not publicly available due to privacy restrictions but are available from the corresponding author on reasonable request.

## CONFLICTS OF INTEREST

PAM received consulting fees from AstraZeneca, GSK, MSD and Pfizer, as well as honoraria from AstraZeneca, Gilead, GSK and MSD. This author also received support for attending meetings abroad from Gilead, GSK, Immedica, Pfizer and Roche and joined a Board/Committee from Abbvie, AstraZeneca, GSK and MSD.

BP received honoraria from GlaxoSmithKline and Novartis to provide lectures on cancer-related themes. This author also received support from Pfizer, Merck and AstraZeneca to attend meetings abroad.

CC received consulting fees from AstraZeneca and honoraria for lectures from Novartis.

MF received support from Technimed to attend the EFIC Congress in September 2023, namely for travel, hotel stay and

registration in the event.

FV received honoraria from GSK (2025) to write a partial text in the “*Guia do Cancro do Endométrio*”; from Pierre Fabre (2024 and 2025) to join the Scientific Evaluation Committee of “Poster Revolution Awards”; from Abbvie (2025) for lectures and training on the diagnosis and treatment of ovarian cancer; from Roche (2024) to lecture on cancer prevention; from Astra Zeneca (2024) to lecture on a training for nurses working with hereditary cancer patients. This author also coordinated the Hereditary Cancer Group of the Portuguese Society of Clinical Oncology (*pro bono*).

IV, CP, SM, CR have no conflicts of interest to declare.

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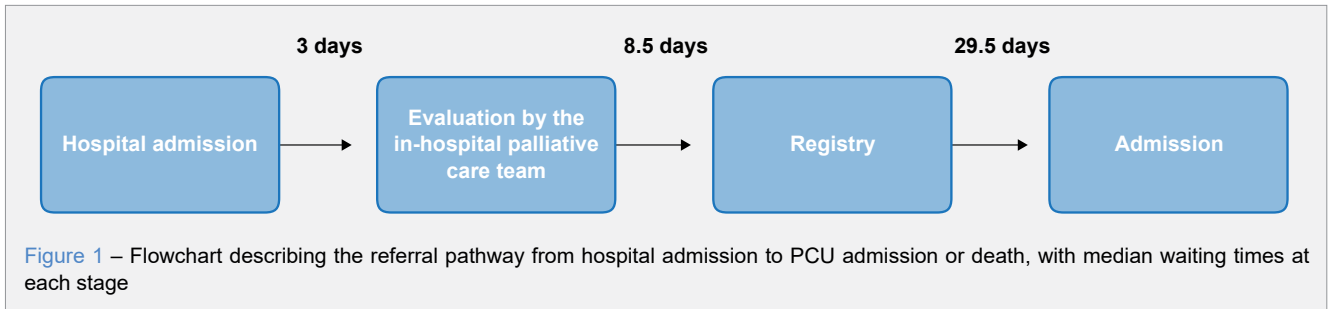
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**Table 1** – Sociodemographic characteristics and main referral pathway times of oncology inpatients referred to specialized palliative care units

Variable	Overall (n = 208)
<b>Age, median (IQR)</b>	70 (62 – 78)
<b>Female sex, n (%)</b>	135 (64.9)
<b>Main tumor type, n (%)</b>	
Head & neck	45 (21.6)
Breast	37 (17.8)
Gastrointestinal	36 (17.3)
Gynecological	34 (16.3)
<b>Referral outcome, n (%)</b>	
Admitted to PCU	77 (37.0)
Died before admission	131 (63.0)
<b>Referral → PCU admission, days, median (IQR)</b>	29.5 (20.0 – 41.0)
<b>Referral → death (non-admitted), days, median (IQR)</b>	34.0 (20.0 – 54.0)
<b>PCU length of stay, days, median (IQR)</b>	21.5 (10.0 – 40.5)

This table summarizes the sociodemographic characteristics of oncology inpatients referred to specialized palliative care units, their referral outcomes and overall waiting times from referral to admission or death. Continuous variables are presented as medians with IQR, and categorical variables as absolute frequencies and percentages. IQR: interquartile range; PCU: palliative care unit.



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