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# Home death *versus* hospital death: a retrospective analysis of patients in palliative care

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## Abstract

Respecting the patient's preferred place of death is a key indicator of the quality of palliative care. However, clinical factors may influence this outcome. This study aimed to compare the clinical profiles, symptom burden, and medical interventions of patients who died at home *versus* those who died in an inpatient setting (hospital) within the context of a Brazilian public healthcare institution. A retrospective study was conducted involving 227 patients who were followed by the Palliative Care Team at the Instituto de Assistência Médica ao Servidor Público Estadual (IAMSPE). Sociodemographic and clinical variables, symptom control, and pharmacological interventions were analyzed using generalized linear mixed models (GLMMs). Of these patients, 59.47% (n=135) died in the hospital ward and 40.53% (n=92) died at home. No statistically significant differences were observed between age or sex and place of death. Hospitalized patients presented with a greater number of symptoms, although no significant differences were found for pain and dyspnea. Most of the patients also had multiple metastases. The use of oxygen was significantly higher in the inpatient setting, while oral and enteral feeding was more feasible at home. Although the total number of medications administered was higher in the hospital, there were no significant differences in the use of morphine and midazolam between the groups. In conclusion, clinical severity was a key factor influencing hospitalization until death. Despite equivalent symptom control between settings, expanding access to structured home-based palliative care could enable patients to experience end-of-life care aligned with their preferences.

Key words: Clinical profile; Death; Home; Hospital; Inpatient death; Palliative care

## Introduction

Palliative care is a healthcare approach focused on relieving suffering and enhancing the quality of life for patients with severe, life-limiting illnesses (1,2). For maximum effectiveness, palliative care should be initiated early, ensuring a comprehensive assessment of patients and appropriate management of physical, psychosocial, and existential symptoms (3). This model not only addresses clinical needs but also supports emotional and existential aspects, providing individualized and compassionate care. Identifying the need for palliative care can be supported by epidemiological analyses, which use mortality data and the frequency of end-of-life symptoms to improve service planning and ensure support is provided to all who require it (1,4).

Respect for patients' individual preferences, particularly concerning their preferred place of death, constitutes a fundamental principle of palliative care and significantly influences the end-of-life experience (5). However, research consistently indicates a disparity between patients' expressed wishes and the actual care received (6–11). The ability to choose the place of death is not equally available to all patients and may be affected by socioeconomic factors and disparities in access to adequate care (12,13). Recent studies suggest that having a partner, maintaining frequent contact with healthcare providers in the final week of life, and continuity of care increase the likelihood of dying in the preferred setting, whereas other conditions can reduce this probability (7,9,13,14). Understanding the barriers and facilitators to honor these preferences is essential for improving palliative care that respects patients' dignity, values, and choices, irrespective of their clinical or social circumstances. This challenge is also evident in international contexts, as seen in Germany, where, despite

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growing access to palliative care, a high percentage of patients still die in hospitals, particularly men and those without structured home-based care options (15).

Despite the formal incorporation of palliative care into the Brazilian Unified Health System (Sistema Único de Saúde – SUS) via Resolution No. 41/2018, the implementation of palliative services still faces significant challenges. A notable impediment is the absence of a structured network to support home deaths (16,17). While many countries have experienced an increase in home deaths due to the expansion of home-based palliative care services (18), Brazil continues to see a predominance of hospital deaths, even among patients who express a desire to die at home (15,16). For example, in São Paulo, between 2006 and 2012, 88.2% of elderly patients with oncological diseases died in hospitals (16), reflecting the limitations of the healthcare infrastructure and highlighting the need for more expressive investment in palliative care services.

The Instituto de Assistência Médica ao Servidor Público Estadual (IAMSPE) offers an integrated model combining hospital and home-based care. This approach enables terminally ill patients to receive support aligned with their individual preferences (19). The institution's hospital data have been instrumental in generating scientific evidence to inform public policy and strengthen the development of Brazil's palliative care network (19). Such data provide valuable insights into the factors that either impede or facilitate home deaths, thereby supporting efforts to uphold patients' end-of-life choices.

Given the significance of palliative care and the challenges associated with ensuring home deaths in Brazil, this study aimed to compare the clinical profiles, resource utilization, and factors associated with dying at home versus in an inpatient setting. Through a retrospective chart review, we sought to identify favorable conditions and obstacles to implementing a home-based palliative care model.

## Material and Methods

This study was conducted at IAMSPE, a public healthcare institution maintained by the Government of the State of São Paulo, Brazil. The institution provides medical services at no additional cost to state public servants and their dependents. Access to the Palliative Care Service within IAMSPE typically occurs through internal referrals, especially from other specialties responsible for managing the patient's primary illness (e.g., oncology). At the time of the study, the service was not open to patients from outside IAMSPE (i.e., from other public or private healthcare systems).

This retrospective study received approval from the Research Ethics Committee of IAMSPE (Protocol No. 071854/2021). As it was a retrospective study based on medical records, the requirement for informed consent was waived by the committee in accordance with national regulations.

We reviewed the medical records of 227 patients cared for by the Palliative Care Team at IAMSPE, who died either at home or in the inpatient unit between March 2019 and March 2021. Data collection was carried out over a six-month period in 2021, based on documentation related to these deaths.

We included patients aged 18 years or older who were registered in the IAMSPE Palliative Care Service. Exclusion criteria were patients under 18 years of age, those who died due to SARS-CoV-2 (COVID-19), and those under the care of other medical teams.

Data were collected from the electronic system Soul MV and supplemented by manual records archived in patient charts. The variables analyzed included: 1) *Patient clinical profiles*: sex, age, primary diagnosis, length of follow-up, and age at death. 2) *Reported symptoms*: dyspnea, pain, fatigue, nausea, depression, anxiety, drowsiness, hypoactive delirium, hyperactive delirium, mixed delirium, edema, wound infection, cough, diarrhea, constipation, urinary symptoms, dysphagia/choking, ascites, hypersalivation, xerostomia, crackles, odynophagia, bleeding, spasms, seizures, tachycardia, aggressiveness, insomnia, malaise, vomiting, unspecified delirium, weakness, fever, hyporexia, agitation, dizziness, chills, hypotension, hyperemia, sweating, myoclonus, desaturation, colic, burning sensation, and cachexia. 3) *Administered treatments and medications*: midazolam, morphine, methadone, dipyrone, fentanyl, citalopram, ondansetron, phenytoin, topiramate, haloperidol, mirtazapine, clonazepam, venlafaxine, lorazepam, quetiapine, fluoxetine, omeprazole, gabapentin, lamotrigine, tramadol, loperamide, scopolamine, simethicone, atropine, bisacodyl, furosemide, chlorpromazine, antibiotics, anticoagulants, pantoprazole, cilostazol, pregabalin, lactulose, ketoprofen, hyoscine, enemas, metoclopramide, dexamethasone, dimenhydrinate, phenobarbital, atenolol, losartan, codeine, sodium picosulfate, betamethasone, carvedilol, spironolactone, atorvastatin, dabigatran, macrogol, trimetazidine, tranexamic acid, octreotide, acetylcysteine, zolpidem, and diazepam. 4) *Received interventions*: phone calls and home visits, including the total length of follow-up by the Palliative Care Team.

### Statistical analyses

All statistical analyses were conducted using RStudio version 4.4.1, adopting a 5% significance level. Generalized Linear Mixed Models (GLMMs) were used to assess the effect of place of death (home *vs* hospital) on several clinical and demographic variables. While logistic regression could be considered a simpler analytical option, GLMMs were selected due to the hierarchical structure of the data, potential intra-subject variability, and missing

data points, characteristics that are better addressed by mixed-effects modeling frameworks. The dependent variables modeled included the presence of metastases (hepatic, bone, pulmonary), use of oxygen supplementation, oral feeding viability, total number of symptoms ($\geqslant 6$ *vs* $<6$), specific symptoms such as pain and dyspnea, and use of medications such as morphine and midazolam (yes/no). The independent variable in each model was place of death. Binomial error distributions were used for binary outcomes, and model fit was assessed via residual analysis.

The variance explained by fixed effects and by the full model (fixed and random effects combined) was estimated using marginal ($R^2$m) and conditional ($R^2$c) $R^2$ coefficients, calculated with the MuMIn package. $R^2$ values of approximately 0.02, 0.13, and 0.26 were interpreted as small, medium, and large effects, respectively (20). Pairwise comparisons were performed using estimated marginal means (EMMs) via the emmeans package.

Continuous variables such as the number of phone calls received, length of follow-up, number of metastatic sites, time between the last home visit and death, and number of home visits were compared using Student's *t*-tests.

For the global analysis of symptoms and medications, patients were classified according to the presence of fewer than six ($<6$) or six or more ($\geqslant 6$) symptoms/medications, and associations with place of death were tested using binomial GLMMs followed by Tukey's HSD *post hoc* tests, when appropriate.

## Results

### Patient characteristics

The study analyzed a total of 227 patients followed by the Palliative Care Team at IAMSPE, of whom 59.47% (n=135) died in the hospital unit and 40.53% (n=92) died at home.

As shown in Table 1, 48.46% (n=110) of the patients were male and 51.54% (n=117) were female. Among male patients, 43.64% (n=48) died at home, while 56.36% (n=62) died in the inpatient setting. Among female patients, most deaths occurred in the hospital (62.39%, n=73), whereas 37.61% (n=44) died at home. These findings showed a higher proportion of inpatient deaths across both sexes, with no statistically significant association between sex and place of death (P=0.4298).

In terms of age distribution, 5.73% (n=13) of patients were aged 18–49 years, 9.25% (n=21) were 50–59 years old, 26.87% (n=61) were 60–69 years old, 27.75% (n=63) were 70–79 years old, 22.91% (n=52) were 80–89 years old, and 7.49% (n=17) were aged 90 years or older. Among patients aged 50 years or older, 42.06% (n=90) died at home and 57.94% (n=124) in the hospital. Among those younger than 50, 15.38% (n=2) died at home and 84.62% (n=11) in the hospital, as shown in Table 1. Although home deaths were less frequent among younger patients, no statistically significant difference was found between age and place of death (P=0.1072).

**Table 1.** Sociodemographic and clinical variables according to place of death.

| Sociodemographic variables | Home (n=92) | Hospital (n=135) | P-value |
|---|---|---|---|
| Variable | | | |
| Female sex, n (%) | 44 (37.6) | 73 (62.4) | 0.4298 |
| Male sex, n (%) | 48 (43.6) | 62 (56.4) | 0.623 |
| Age $\geqslant$50 years, n (%) | 90 (42.1) | 124 (57.9) | 0.1072 |
| Age 18–49 years, n (%) | 2 (15.4) | 11 (84.6) | 0.0012 |
| Disease severity and clinical status | | | |
| $\geqslant$2 metastatic sites, n (%) | 37 (40.2) | 98 (72.6) | $<$0.001 |
| Liver metastasis, n (%) | 17 (18.5) | 111 (82.2) | $<$0.001 |
| Bone metastasis, n (%) | 59 (64.1) | 49 (36.3) | 0.006 |
| Lung metastasis, n (%) | 39 (42.4) | 78 (57.8) | 0.017 |
| Any metastasis, n (%) | 31 (33.7) | 89 (65.9) | 0.020 |
| $O_2$ supplementation, n (%) | 13 (14.1) | 116 (85.9) | $<$0.001 |
| Oral/enteral intake viability, n (%) | 76 (82.6) | 23 (17.0) | $<$0.001 |
| Palliative care follow-up variables | | | |
| Follow-up duration (days), mean ± SD | 247.10 ± 395.91 | 230.82 ± 349.13 | 0.75 |
| Interval between last visit and death (days), mean ± SD | 36.40 ± 44.13 | 47.69 ± 53.78 | 0.07 |
| Number of phone calls, mean ± SD | 1.66 ± 1.49 | 1.52 ± 1.35 | 0.45 |
| Number of home visits, mean ± SD | 2.21 ± 4.21 | 1.85 ± 3.87 | 0.49 |

Categorical variables are reported as n (%), and continuous variables are reported as means ± SD. P-values refer to comparisons between groups, using chi-squared test or Student's *t*-test according to variable type. A significance level of 5% was adopted.

The mean duration of follow-up by the Palliative Care Team was similar between groups (P=0.75), as was the interval between the last home visit and death (P=0.07). Additionally, there were no significant differences in the number of home visits (P=0.49) or in the mean number of follow-up phone calls (P=0.45).

Overall, these findings suggest that the level of support provided by the Palliative Care Team, in terms of interactions and monitoring, was similar for patients who died at home and those who died in the inpatient setting.

### Cause and place of death

There was a significant difference in the presence of metastases between patients who died at home and those who died in the inpatient setting, as shown in Table 1. Patients with two or more metastatic sites were more likely to die in the hospital ($P<0.001$). The incidence of specific metastatic sites was also higher among patients who died in the hospital, including liver metastases (OR=20.40, 95%CI: 10.27–40.56, $P<0.001$), bone metastases (OR=1.05, 95%CI: 0.61–1.82, P=0.006), and lung metastases (OR=1.86, 95%CI: 1.09–3.18, P=0.017). Additionally, the need for oxygen supplementation was substantially more frequent in hospital deaths (OR=37.10, 95%CI: 17.33–79.43, $P<0.001$). In contrast, the viability of oral or enteral feeding was significantly greater among patients who died at home (OR=0.03, 95%CI: 0.017–0.071, $P<0.001$).

### Symptoms and place of death

The comparison of symptoms between groups revealed a significant difference in the total number of symptoms presented by patients prior to death (P=0.0003), with a higher frequency of symptoms observed among patients who died in the hospital. However, when analyzing specific symptoms, no statistically significant differences were found between the groups regarding pain (P=0.826) or dyspnea (P=0.581).

### Medications and place of death

The analysis of medication used between groups revealed a greater number of medications administered by patients who died in the inpatient setting compared to the home set ($P<0.001$). However, when evaluating specific drugs, the use of morphine (P=0.135) or midazolam (P=0.486) was similar between groups.

A small number of patients were not included in some graphs due to missing information in their medical records, with no significant impact on the overall analysis.

## Discussion

Our findings indicated that clinical severity was a primary determinant for hospitalization and underscored the critical need for palliative care services to offer appropriate support across all care settings (Table 2) (21). These results are consistent with the existing literature, which highlights that patients in more advanced stages of disease, especially those with multiple organ involvement, require greater clinical support, often justifying hospital stays until death (22–25). A German study revealed that patients treated in certified cancer centers with integrated palliative care were more likely to die in clinical settings, reinforcing the association between care complexity and hospital death prevalence (15). Studies conducted in the United Kingdom and Canada have shown that the complexity of the clinical condition directly influences the place of death, with patients requiring more intensive palliative interventions tending to die in hospitals, even in countries with well-structured home-based palliative care systems (18,25,26). A study conducted by Gomes et al. (27) indicated that most patients with advanced cancer express a preference for home death when circumstances permit, with reported home death preferences ranging from 51 to 84%. However, the present study's findings suggest that, in practice, patients with more advanced disease, especially those with multiple metastases and requiring ventilatory support, have a higher prevalence of hospital deaths. This discrepancy between preference and reality may be related to clinical severity, socioeconomic conditions, and the need for continuous medical support, often making hospitalization inevitable (14). Furthermore, in the Brazilian context, structural challenges such as limited availability of specialized home-based palliative care services and

**Table 2.** Eligibility criteria for palliative care by place of death.

| Factors | Home | | Hospital | |
|---|---|---|---|---|
| | n | % | n | % |
| Advanced/incurable disease | 92 | 100.0 | 135 | 100.0 |
| Symptom burden ($\geqslant$6 symptoms) | 58 | 63.0 | 109 | 80.7 |
| Medication burden ($\geqslant$6 drugs) | 67 | 72.8 | 123 | 91.1 |
| Eligibility by oral feeding | 76 | 82.6 | 19 | 14.1 |
| Eligibility by $O_2$ supplementation | 13 | 14.1 | 116 | 85.9 |
| Eligibility by $\geqslant$2 metastatic sites | 37 | 40.2 | 98 | 72.6 |

difficulties accessing palliative resources at home likely contribute to higher rates of hospitalizations at the end of life (5).

The results revealed a significantly higher frequency of oxygen supplementation among patients who died in an inpatient setting. However, recent research has questioned the effectiveness of oxygen as a universal palliative intervention, suggesting that its routine administration may not provide clinical benefits for all patients (28,29). Although patients who died in the hospital demonstrated a greater overall symptom burden (30,31), no significant differences were found between groups for key symptoms like pain and dyspnea. This indicates that well-structured symptom management can mitigate suffering irrespective of the care setting (32,33). Additionally, while hospitalized patients received a greater total number of medications, no significant differences were observed in the use of essential drugs, such as morphine and midazolam, underscoring that appropriate palliative pharmacological support is feasible in both hospital and home settings when appropriate resources are available (34–36). These findings highlight persistent barriers in Brazil, including limited access to parenteral medications at home and bureaucratic challenges to opioid prescriptions, contributing to unnecessary hospitalizations at the end of life (36). International efforts to standardize palliative care practices, such as the implementation of Canadian guidelines for the withdrawal of life-sustaining therapy in ICUs, have demonstrated that symptom control and holistic care can be successfully incorporated into high-intensity care environments, further validating the feasibility of quality care outside traditional settings (37).

These findings reinforce the importance of expanding access to palliative care services that are capable of honoring patients' preferences and providing adequate support across different care settings. Evidence clearly demonstrates that socioeconomic factors significantly impact access to a patient's preferred place of death. Specifically, a lack of social support and informal caregivers has been shown to reduce the likelihood of dying in the desired setting (12,14,17,37). In the United Kingdom, for instance, qualitative studies have demonstrated that the absence of a structured support network and changes in patient preferences throughout disease progression often hinder the realization of patients' wishes regarding the place of death (38). In Brazil, despite advances in public policies, exemplified by the recent implementation of the National Palliative Care Policy within the SUS, substantial structural challenges endure, including unequal service distribution, a shortage of trained palliative care teams, and limited access to essential medications for symptom control in home settings (16,17).

Implementing strategies to strengthen palliative care within primary healthcare and community-based services could help minimize unnecessary hospitalizations and improve the quality of end-of-life care (34,36). Early access to specialized palliative care teams can reduce hospital burden, enhance symptom management, and offer greater comfort to patients and their families (16,17).

The primary strength of this study lies in the analysis of real-world clinical data from a specialized palliative care team, enabling a comprehensive comparison of symptom burden and medical interventions between inpatient and home-based deaths. Additionally, the study provides valuable insights into end-of-life care in the Brazilian public health system, where such analyses are still scarce. However, some limitations must be acknowledged. The study was conducted in a single institution in Brazil, which may limit the generalizability of the findings to other settings or regions. Furthermore, retrospective data collection based on medical records may be subject to information bias due to incomplete documentation.

Despite recent policy efforts in Brazil, structural barriers persist. Similarly, in China, the lack of structured home-based care for advanced cancer patients also leads to hospital-centric end-of-life experiences, especially in the absence of comprehensive palliative training for nurses (39). These international parallels reinforce the global relevance of investing in professional training and home-care infrastructure to ensure that palliative care is delivered following patients' preferences.

This study demonstrated that patients with a higher symptom burden, greater demand for medications, multiple metastases, and a need for supplemental oxygen support had a higher prevalence of hospital deaths. In contrast, those with viable oral or enteral feeding were more likely to die at home. Moreover, the management of pain and dyspnea, as well as the use of morphine and midazolam, was similar between groups, suggesting that either hospital or home settings may deliver effective palliative care, provided that appropriate resources are available. These findings reinforce the importance of strengthening home-based palliative care teams, expanding access to essential medications, and integrating different levels of healthcare services to ensure that patients' preferences are respected and quality end-of-life care is provided across all settings.

**Conflicts of Interest:** The authors declare that there were no conflicts of interest related to this study.

**Data Availability:** The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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**Authors**' **Contributions:** R.D. Bittencourt was responsible for data organization and analysis, as well as drafting the manuscript. S. Krasilcic contributed to the manuscript writing and critical revisions. I.M. da Silva participated in reviewing the data analyses and contributed to the writing. M.K. Koike supervised all stages of the research and guided the development of the manuscript.

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