

# Profile of patients under palliative care in home care in a service in Southern Brazil

Perfil dos pacientes em cuidados paliativos na atenção domiciliar em um serviço do Sul do Brasil Perfil de pacientes en cuidados paliativos en atención domiciliaria en un servicio del Sur de Brasil

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#### **Abstract**

Introduction: Family Practice, being closer to the patient, can offer comprehensive and individualized Palliative Care (PC). Therefore, characterizing the population served becomes essential to support the development and implementation of strategies to expand PC services in the Health Care Network. Objective: Present an overview of the epidemiological profile of patients receiving homebased palliative care from January 2018 to October 2021, supported by Home Care Services (HCS) affiliated with Hospital Municipal São José (HMSJ) in the city of Joinville (SC). Methods: Retrospective case series with Participants in HCS who passed away during the study period were included. Exclusion criteria comprised living participants, those registered but not attended by the medical team, program discharges, incomplete medical records, duplicates, and individuals under 18 years of age. Collected data included record identifier, age, gender, marital status, diagnosis, entry and death dates, duration of HCS stay, death outcome and certification method, opioid analgesia use, use of multiple opioids, and use of continuous infusion pump (CIP) analgesia and/or palliative sedation. Researchers collected and double-checked the coded data, performed average and median calculations, correlated data, and analyzed results. Results: Two hundred and eight patients were included; average age was 66.8 years; neoplastic diseases were most prevalent (94.2%), particularly gastrointestinal (21.1%), pulmonary (12.5%), and breast cancers (9.5%). The majority of patients (37.9%) remained under HCS care for over 30 days, and 75.9% of the analyzed population passed away at home, with 45.67% certified by the Death Verification Service and 30.2% by HCS. Regarding pain management, 87.1% used opioids, most commonly morphine. Palliative sedation was present in only 25.48%, predominantly using midazolam. Conclusions: This study found a higher prevalence of patients with end-stage neoplastic diseases requiring adequate pain control, an area where HCS provides specialized care in a more comfortable environment.

Keywords: Palliative care; Home care services; Home care services, hospital-based; Right to die.

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#### Resumo

Introdução: A Medicina de Família e Comunidade, como forma de cuidado mais próxima ao paciente, pode ofertar cuidados paliativos (CP) de modo integral e individualizado. Assim, torna-se relevante caracterizar a população atendida de modo a favorecer o desenvolvimento e implementação de estratégias para a ampliação da assistência de CP na Rede de Atenção à Saúde. Objetivo: Apresentar um panorama do perfil epidemiológico dos pacientes em CP domiciliares, no período de janeiro de 2018 a outubro de 2021, assistidos pelo Servico de Atenção Domiciliar (SAD), vinculado ao Hospital Municipal de São José (HMSJ), na cidade de Joinville (SC). Métodos: Série de casos retrospectiva, incluindo os participantes do SAD que evoluíram a óbito no período da pesquisa. Os critérios de exclusão foram os participantes vivos no período da pesquisa; aqueles registrados, mas não atendidos pela equipe médica; os que receberam alta do programa; pacientes com prontuário incompleto; prontuários duplicados e menores de 18 anos. Os dados coletados incluíram número identificador do prontuário, idade, sexo, estado civil, diagnóstico, data de entrada no SAD, data de óbito, tempo de permanência no SAD, desfecho de óbito e via pela qual foi atestado o óbito, se recebeu analgesia com opioides e se fez uso de mais de um opioide, e se recebeu analgesia em bomba de infusão contínua (BIC) e/ou sedação paliativa. Os dados foram coletados pelos pesquisadores de prontuários médicos, codificados e conferidos duplamente. Foram realizadas então média e mediana das variáveis, bem como correlação dos dados e análise dos resultados. Resultados: Duzentos e oito pacientes foram incluídos; a média de idade foi 66.8 anos; as doencas neoplásicas foram as mais prevalentes (94,2%), destacando-se as neoplasias de trato gastrointestinal (21,1%), pulmonares (12,5%) e de mama (9,5%). A maior parte dos pacientes (37,9%) permaneceu sob os cuidados do SAD por mais de 30 dias e 75,9% da população analisada veio a óbito em ambiente domiciliar, e 45,67% desses indivíduos foram atestados via Serviço de Verificação de Óbitos e 30,2% via SAD. Quanto ao manejo da dor, 87,1% fizeram uso de opioides, mais frequentemente a morfina. Quanto à sedação paliativa, esta esteve presente em apenas 25,48%, prevalecendo o uso de midazolam. Conclusões: Neste estudo, encontrou-se maior prevalência de pacientes acometidos por doenças neoplásicas em fase final de vida, com necessidade de controle de dor adequado — contexto no qual o SAD possibilita o atendimento especializado ao paciente e seus familiares em um ambiente de maior conforto.

Palavras-chave: Cuidados paliativos; Serviços de assistência domiciliar; Serviços hospitalares de assistência domiciliar; Direito a morrer.

#### Resumen

Introducción: La Medicina Familiar y Comunitaria, como forma de atención más cercana al paciente, puede ofrecer Cuidados Paliativos (CP) de forma integral e individualizada. Por lo tanto, resulta relevante caracterizar la población atendida con el fin de favorecer el desarrollo e implementación de estrategias para ampliar la asistencia en CP en la red de Atención a la Salud. Objetivo: Presentar una visión general del perfil epidemiológico de los pacientes que recibieron cuidados paliativos domiciliarios, de enero de 2018 a octubre de 2021, atendidos por el Servicio de Atención de Salud a Domicilio (SAD), vinculado al Hospital Municipal São José (HMSJ), de la ciudad de Joinville (SC). Método: Serie de casos retrospectiva, incluyendo participantes del SAD que fallecieron durante el período de investigación. Los criterios de exclusión fueron participantes vivos durante el período de investigación; pacientes registrados pero no atendidos por el equipo médico; los que tuvieron alta del programa; con historial médico incompleto, historial médico duplicado y menores de 18 años. Los datos recogidos incluyeron número de identificación del historial médico, edad, sexo, estado civil, diagnóstico, fecha de ingreso al SAD, fecha de fallecimiento, tiempo de estancia en el SAD, desenlace de la muerte y vía por la que se certificó la muerte; si recibió analgesia con opioides y si usaron más de un opioide, y si recibieron analgesia con bomba de infusión continua (BIC) y/o sedación paliativa. Los datos fueron recopilados por investigadores de registros médicos, codificados y verificados dos veces. Luego se realizó la media y mediana de las variables, así como la correlación de datos y el análisis de los resultados. Resultados: Se incluyeron doscientos ocho pacientes; la edad promedio fue de 66,8 años; las enfermedades neoplásicas fueron las más prevalentes (94,2%), destacándose las neoplasias del tracto gastrointestinal (21,1%), pulmón (12,5%) y mama (9,5%). La mayoría de los pacientes (37,9%) permanecieron bajo atención del SAD más de 30 días y el 75,9% de la población analizada falleció en su domicilio, de los cuales el 45,67% fue certificado a través del Servicio de Urgencias de Verificación de Defunciones y el 30,2% a través del SAD. En cuanto al manejo del dolor, el 87,1% utilizaba opioides, con mayor frecuencia morfina. En cuanto a la sedación paliativa, estuvo presente solo en el 25,48%, prevaleciendo el uso de midazolam. Conclusiones: En este estudio se encontró una mayor prevalencia de pacientes afectados por enfermedades neoplásicas en la etapa final de la vida, que necesitan un control adecuado del dolor, un contexto en el que el SAD permite una atención especializada a los pacientes y sus familias en un ambiente más confortable.

Palabras clave: Cuidados paliativos; Servicios de atención de salud a domicilio; Servicios de atención a domicilio provisto por hospital; Derecho a morir.

#### INTRODUCTION

Palliative Care (PC) aims to ensure greater dignity for individuals with life-threatening illnesses through a multidisciplinary approach. It seeks to address the patient's needs holistically, including physical, emotional, social, and spiritual aspects, while also providing support to their families, who are considered integral parts of the care unit.<sup>1</sup>

During the illness and end-of-life stages, patients often require complex and individualized care in hospital settings, affecting not only their routines but also their entire family dynamics. Providing support and understanding to the team caring for terminally ill patients is essential for enhancing the quality of care and alleviating suffering in all its dimensions, thereby upholding the patient's dignity and human integrity.<sup>2</sup> In Brazil, as in the rest of the world, there is a growing trend in PC. However, hospitals still provide the majority of care for terminally ill patients, leading to an excess of interventions and invasive procedures.<sup>3</sup> An alternative to expand the reach of hospital PC teams is the Home Care Service (HCS), which offers exclusive and personalized care for various health needs in the comfort of the patient's home.<sup>4</sup> Home care is regulated and defined by Ordinance No. 825, dated April 25, 2016, as a type of health care characterized by actions for disease prevention and treatment, rehabilitation, palliation, and health promotion — delivered at home — to ensure continuity of care.<sup>5</sup>

The advantage of home care lies in its ability to offer integrated care tailored to the patient's needs and preferences, with caregivers focusing entirely on the patient. This provides greater comfort and protection throughout the illness, treatment, death, and grieving processes.<sup>6</sup> Additionally, home care reduces the length of hospital stays, which leads to lower costs, a reduced incidence of nosocomial infections, and fewer unnecessary interventions. It also offers greater emotional support and autonomy for both patients and their family. When providing palliative care through home care, it is crucial for the team to be trained in clear and assertive communication, symptom management, and providing support and instruction to caregivers, with a focus on enhancing the quality of life for patients and their families.<sup>3</sup>

Another important aspect of PC in Brazil is that it is predominantly associated with the tertiary care level. However, Primary Health Care is recognized as the most cost-effective strategy for promoting health.<sup>7</sup> Despite this, PC at the primary care level faces several limitations, including a lack of trained teams, limited access to opioids, inadequate availability of professionals to provide comprehensive multidisciplinary care, and deficiencies in PC education during undergraduate and specialized training for professionals.<sup>8</sup>

Since family and community doctors play a fundamental role in the integrality and individuality of care and are closer to patients, they are professionals capable of performing PC in primary care with extreme quality, as long as they have greater access to the training and tools necessary in this area. In view of this, the Brazilian Society of Family Practice (*Sociedade Brasileira de Medicina de Família e Comunidade* – SBMFC) addresses the topic by creating a competency-based curriculum, which highlights the skills expected of family practice physicians, such as managing pain and complications in terminally ill patients and issues related to death and mourning.<sup>9</sup>

Given the wide range of life-threatening diseases and the increasing number of patients requiring PC, it is essential to understand the epidemiological profile of the population served. This knowledge allows for the more effective implementation of strategies that not only prevent illness but also promote health. Additionally, it helps correlate sociodemographic variability with the profiles of the patients served, thereby enhancing the quality of services provided.<sup>10</sup>

This article aimed to map and identify the profile of PC patients in the Home Care Service of Joinville, Santa Catarina (SC). It also seeks to contribute to the ongoing debate on the current state of PC in Brazil and the necessary improvements related to the expansion and coordination of care.

#### **METHOD**

This is a case series report based on a retrospective analysis of medical records of PC patients treated by the Home Care Service of Joinville, SC, who passed away between January 2018 and October

2021. Approval was obtained from the Research Ethics Committee of Hospital Municipal São José (HMSJ) under Certificate of Presentation for Ethical Appreciation (*Certificado de Apresentação para Apreciação Ética* – CAAE) 47907821.0.0000.5362/Opinion No. 4.778.999. The study also involved the signing of the Term of Commitment for Use and Data Handling.

Patients referred for HCS are directed to the service through several routes: patients from the High Complexity Oncology Care Center at HMSJ — in oncological PC with a Palliative Performance Scale — PPS ≤40; patients admitted to HMSJ Hospital for oncological and non-oncological PC with a PPS ≤40, under a dehospitalization protocol; referrals from Primary Care (Basic Family Health Units — (*Unidade Básica de Saúde da Família* – UBSF) of the municipality); and external demand based on direct patient requests, including those who meet the HCS' predetermined criteria. Of the 60 home care vacancies, 20 are reserved for PC patients. This study included patients who were followed up in the service by PC and who died between January 2018 and October 2021. The temporal inclusion criterion is January 2018 — marking the beginning of PC care within the HMSJ HCS — up to October 2021, the end of the data collection period for the students' coursework. Therefore, there were no patients before the data collection period, as HCS did not have admissions focusing on PC.

Through a comprehensive and careful review of the medical records, the following variables were collected using a data extraction form: medical record identification number, age, gender, marital status, primary diagnosis for which PC was indicated, date of entry into HCS, date of death, length of stay in HCS, outcome according to the place of death (HMSJ, home, or other service), and the method of death certification at home (via the Multidisciplinary Home Care Team — MHCT or Death Notification Service — DNS). Additionally, data were collected on whether the patient received opioid analgesia (codeine, tramadol, morphine, or methadone), whether more than one type of opioid was used during MHCT monitoring, and whether continuous infusion pump (CIP) analgesia and/or palliative sedation with midazolam or thiopental was administered.

Inclusion criteria were as follows: all PC patients treated by the Home Care Service of HMSJ who died between January 2018 and October 2021. Exclusion criteria included patients who were alive during the research period; patients who had only been registered but had not received care (*i.e.*, died before a home medical visit); patients discharged from the program for follow-up at an outpatient clinic or UBSF; patients with incomplete medical records (such as missing data on medication use/date of hospitalization/marital status); duplicate medical records; and patients registered solely for the administration of the last dose of medication at home or for waiting for an imaging exam. It is important to note that, in accordance with the common agreement with the Municipal Health Department, the Joinville HCS includes only patients over 18 years of age. Therefore, this article also excludes patients under 18. Additionally, the study was conducted during the COVID-19 pandemic, but HCS maintained its normal operations throughout this period.

Data collection was conducted by an academic researcher using medical records. Data were entered and coded into a Microsoft Excel spreadsheet and then double-checked by another academic researcher. The data were analyzed after calculating the mean and median of the variables according to their distribution.

The planning, writing, and retrospective analysis of the manuscript were entirely carried out by the researchers, without involvement from the community, patients, or family members. In terms of confidentiality, participants' identities were protected by using initials and medical record numbers, in compliance with data protection laws. Authorization from family members was not required for data collection, as the study was

retrospective and focused on population analysis, with all included patients having death as the outcome. Anonymized data may be shared by contacting the primary researcher via the provided email address.

## **RESULTS**

Among the 237 medical records reviewed, 208 were eligible for analysis, while 29 were excluded based on the criteria specified in the methodology (exclusions included five patients who were alive during the study, 13 who were discharged from the program, five who died before home care could be provided, two with incomplete medical records, one with a duplicate record, and three who were registered solely to complete parenteral medication). Mean age of participants was  $66.8 \pm 15.61$  years; minimum age of 19 years and maximum of 100 years, and median age of 68 years. Most patients were aged, with 46 (22.1%) aged between 80 and 100 years old, and 109 (52.4%) aged between 60 and 79 years old. Additionally, 40 (19.2%) were aged between 40 and 59 years old, and 13 (6.2%) were younger than 40 years old. Regarding gender, 101 (48.5%) were men and 107 (51.4%) were women. In terms of marital status, 26 (12.5%) were single, 112 (53.8%) were married, 27 (12.9%) were divorced, and 43 (20.6%) were widowed.

When correlating gender and marital status, it was observed that married men accounted for the majority (32.2%), while married women accounted for 21.6%, as shown in Table 1.

Regarding the pathologies affecting individuals, neoplasms were predominant (94.2%), while neurological diseases accounted for 4.3%, and other illnesses made up 1.4%, including one individual undergoing post-COVID rehabilitation. Among the neoplastic diseases, 21.1% were of the gastrointestinal tract (GIT), 12.5% were lung cancers, 12.0% were breast cancers, 9.6% were malignancies of the male urogenital system, 8.1% were of the head and neck, 7.6% were urogynecological cancers, 4.3% were central nervous system tumors, and 18.7% corresponded to other neoplasms.

When correlating gender and pathology, it was observed that among women, GIT neoplasms were the most prevalent (25.2%), followed by breast neoplasms (23.3%). Among men, other neoplasms were the most prevalent (23.7%), followed by urogenital neoplasms (19.8%), and both GIT and lung neoplasms, each with prevalence of 16.8%.

Regarding the length of stay under MHCT care, most patients were under care for more than 30 days, accounting for 37.9% of the sample. Patients who spent less time were divided into two groups: 37.5% were under care for a period between seven and 30 days, and 24.5% were under care for less

**Table 1.** Stratification of the sample by gender and marital status and the equivalent percentage in the total sample and the specific group.

Gender and marital status	% of total men	% of the studied sample	
Single men	12.87	12.87 6.25	
Married men	66.33	32.21	
Divorced men	14.85	7.21	
Widowed men	5.94 2.88		
Gender and marital status	% of total women	% of the studied sample	
Single women	12.15	6.25	
Married women	42.05	21.63	
Divorced women	11.21	11.21 5.77	
Widowed women	34.58 14.90		

than seven days. It was observed that the pathologies associated with stays for longer than 30 days included breast neoplasms, urogynecological neoplasms, head and neck neoplasms, and male urogenital neoplasms, as detailed in Table 2.

When analyzing the place of death, it was found that 75.9% of deaths occurred at home, with 30.2% certified by MHCT itself and 45.6% certified by the DNS. Additionally, 18.7% of deaths occurred in HMSJ, and 5.2% occurred in other services.

The majority of individuals (83.1%) used opioids in the final stages of life. Among these, strong analgesics were predominant, with morphine being the most commonly used (66.8%) and methadone used by 6.7%. In terms of weak opioids, 8.1% of patients used codeine, and only 1.4% used tramadol.

Regarding analgesia with CIP, 43.7% of individuals did not use it. Among those who did, 54.3% received morphine, and only 1.9% received fentanyl.

Finally, the use of palliative sedation was analyzed. Most patients in the total sample did not receive palliative sedation (74.5%). Among those who did, 25% used midazolam, and only one participant (0.48%) used thiopental.

## DISCUSSION

Mean age of individuals in this study was  $66.8 (\pm 15.61)$  years, with a majority being women. A similar study conducted with 63 patients in Porto Alegre, which analyzed PC for cancer patients in a public home care service, found a mean age of  $66 (\pm 11.6)$  years, 11 indicating comparable results in terms of age. However, the Porto Alegre study had a higher percentage of male patients (60%), contrasting with the current study, where the majority of patients were female. In another study conducted in Pelotas, Rio Grande do Sul (RS), 12 which characterized a home hospitalization and PC program at the Brazilian Unified Health System (Sistema Único de Saúde – SUS), 12 56.0% of the 213 patients were male, 50.0% were under 59 years of age, and 41.0% were between 60 and 70 years old. These findings differ from the current study's results, highlighting that each service exhibits unique characteristics based on its specific population and region.

Most individuals in the present study were monitored by the service for more than 30 days. In contrast, a cross-sectional study of all adult patients undergoing cancer PC, conducted by the Conceição Hospital

**Table 2.** Analysis of the percentage of patients monitored by the Home Care Service/Multidisciplinary Home Care Team over a certain period and by pathology.

Pathology/length of stay	Less than 7 days (%)	Between 7 and 30 days (%)	More than 30 days (%)
Breast cancer	32.00	28.00	40.00
CNS cancer	22.22	55.56	22.22
Urogynecological cancers	25.00	31.25	43.75
Lung cancer	23.08	50.00	26.92
Head and neck cancer	17.65	23.53	58.82
GIT cancer	22.73	45.45	31.82
Male urogenital cancers	25.00	35.00	40.00
Other cancers	28.21	33.33	38.46
Neurological diseases	0.00	44.44	55.56
Other pathologies	66.67	0.00	33.33

CNS: central nervous system; GIT: gastrointestinal tract.

Group Home Care Program, reported a median follow-up time of 22 days.<sup>11</sup> This longer duration of care in the current study is a positive indicator, reflecting the effectiveness of the multidisciplinary approach to PC. It suggests that care can be provided with greater availability and comprehensiveness until the patient's death.

Regarding the PC approach to different diseases, the high prevalence of neoplasms is well-documented. A study conducted in Pelotas, which focused on comprehensive care for SUS cancer patients, stratified the highest prevalence of cancers by gender. For men, the most common were lung cancer (24.0%), head and neck cancer (13.0%), and intestinal cancer (10.0%). For women, the most prevalent cancers were breast cancer (22.0%), intestinal cancer (10.0%), and lung cancer (9.0%). In the present study, among women, GIT neoplasms were the most common, followed by breast neoplasms and urogynecological neoplasms, partially aligning with the Pelotas study. For men, however, the study revealed a different pattern. The predominant neoplasms were classified under other types (including skin cancers, metastatic cancers of unknown primary origin, and sarcomas, and others), followed by urogenital cancers, and then GIT and lung cancers. This variation highlights the need for further studies that stratify such variables to enhance data analysis and correlation.

Given the predominance of cancer patients, it is important to emphasize the high prevalence of pain associated with neoplastic diseases and to analyze the treatments used to control this pain. Pain affects up to 80% of cancer patients, being more frequent in those with advanced disease, though it can affect around 30% of patients from the time of diagnosis.14 The WHO, in 1986, classified cancer pain as a global medical emergency and published guidelines for pain control, introducing the analgesic ladder that is still in use today. The guidelines recommend oral administration of medications at fixed intervals tailored to each patient's specific needs. Opioids are included in the second and third steps of the ladder, categorized as weak (codeine and tramadol) and strong (morphine, methadone, fentanyl), respectively, with non-opioid analgesics following. 14 The National Consensus on Oncological Pain, in line with WHO guidelines, underscores the importance of evaluating the type, characteristics, and intensity of pain for better treatment indications. Opioid drugs, as broad-spectrum analgesics, are recommended for both nociceptive and neuropathic pain, which are commonly present in mixed forms in cancer patients. 15 In the present analysis of medical records, it was noted that 83.1% of patients were prescribed oral opioid analgesics, with morphine being the most commonly used, followed by codeine and, to a lesser extent, tramadol. These findings align with other studies conducted by Brazilian institutions on pain management in cancer patients, including a survey in Pelotas, RS, on palliative care patients treated by the Melhor em Casa Program. This study also revealed that over 80% of patients used opioids for analgesia, with 45% using strong opioids, 45% using weak opioids, and 10% using common analgesics. About 10% of patients required a combination of opioids and analgesics. 12 A relevant issue in analgesia is the limitation in the supply of opioids and concerns about substance abuse, which complicate pain management in PC. The distribution of these medications is managed by State Health Departments or qualified hospitals, which can be challenging for patients with limited access and mobility.<sup>16</sup> To address these issues, the Palliative Care Unit of the José Alencar Gomes da Silva National Cancer Institute (Instituto Nacional do Câncer José Alencar Gomes da Silva – INCA) began integrating with Primary Health Care (PHC) in 2017. This initiative aimed to ensure continuity of care in patients' home settings. Eligible patients were referred to the PHC with written details of their clinical condition for home visits. Information about the care provided was documented by the PHC team and sent to the INCA outpatient clinic, where adjustments to the management plan were made, reducing the need for travel while maintaining continuity of care. 17

Thus, it is crucial to understand opioid drugs and manage potential side effects effectively. Adapting treatment to the home environment, integrating different levels of health care, and educating family members/caregivers, and patients about the risks-benefits of opioid use are essential. The goal is to ensure good adherence to the prescribed treatment, efficient symptom control, and improved quality of life for patients, which are vital for the effective practice of PC.

Regarding palliative sedation, according to literature, it is typically indicated for patients with refractory symptoms, incurable diseases, and a limited life expectancy when other treatment options have been exhausted. Palliative sedation aims to alleviate intolerable suffering, often caused by refractory symptoms such as delirium, dyspnea, vomiting, and pain. In the present study, most patients did not use palliative sedation. However, among those who did, 25.0% were administered midazolam, and 0.48% received thiopental. A descriptive and retrospective study conducted with 36 patients in São Paulo, mentioned in the literature review, also investigated palliative sedation in terminally ill patients at home. The study used drugs such as midazolam, morphine, haloperidol, transdermal fentanyl, and promethazine, with a median sedation duration of three days. Several factors should guide the decision to use palliative sedation, including the severity and onset of symptoms, the appropriateness of the medication, patient autonomy, and shared decision-making with the family. It is crucial to clearly communicate the indications and potential implications of the procedure, such as restricted verbal communication and possible irreversible loss of consciousness.

When addressing patients in the final stage of life, it is crucial to consider the preparation and support needed during the dying process. A key aspect involves discussing the patient's preferences regarding the terminal care they wish to receive, including where they prefer to be cared for and where they would like to spend their final moments. Despite the variability in available literature, it is generally observed that most people prefer to die at home, and this preference remains consistent over time.<sup>20</sup> In light of this, it is essential to explore ways to enhance access to multidisciplinary and qualified home care. This approach emphasizes the need for individualized care that respects the unique circumstances of each patient and the different stages of their care journey. Data from the present study indicate that more than 70% of patients whose medical records were reviewed died at home. Of these, 30.2% were certified by HCS and 46.6% by DNS. Additionally, 18.7% of the patients died at HMSJ, while the remainder passed away in other facilities. These findings highlight the importance of home support in fulfilling the patient's anticipated wishes, including their preference for the place of death. A study conducted in Rio Grande do Sul, within the home care service of the Hospital Conceição Group, found that only three out of 63 patients died at home, largely due to complications necessitating hospitalization before death.<sup>11</sup> Another study, involving 126 terminal patients among 715 patients, reported that 59.5% died at home. However, a significant percentage, over 40%, died in a hospital setting. This was often due to family members' concerns about the adequacy of support at home during the patient's final moments, despite thorough counseling about this vulnerable situation.<sup>21</sup> These observations underscore the individuality of each patient during the illness process and the importance of a cohesive care team in respecting the unique wishes of the patient and their family, including the desire for the place of death.

In conclusion, the majority of patients served were in the final stages of life due to neoplastic diseases, with pain management being a primary concern. HCS facilitates comprehensive care for these patients and their families, providing home monitoring and respecting the patients' wishes concerning their illness and death. However, this service is not universally available across the country and has a limited capacity, despite the increasing demand for palliative care not only for cancer patients but also for those with other life-threatening conditions.

It is hoped that the data from this study will assist other services linked to tertiary care, as well as PHC, by fostering discussions and creating strategies to expand assistance. Despite the research's limitations, it is suggested that patients with longer stays in the service reflect early access to the system, thereby receiving appropriate healthcare with extended support during illness. The study's limitations include a small, non-probabilistic sample, which precludes making inferences for other tertiary hospitals or PHC settings. It is also noted that HCS in Brazil differ in terms of resources, team composition, populations served, and training. Additionally, as with any cross-sectional study, causality cannot be established, though the study may generate hypotheses. Further stratification of variables could provide a more comprehensive analysis of the results. While home PC is well-defined, additional research with more indepth study designs is necessary to better characterize the profile of patients receiving PC in Brazil. Future analyses should also focus on quality of life, assistance in dying, family support, symptom management, and bereavement support, to identify necessary improvements in the system.

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## **CONFLICT OF INTERESTS**

Nothing to declare.

#### **AUTHORS' CONTRIBUTIONS**

SB, FK, MFF, VE: Conceptualization, Data Curation, Methodology. FK, MFF, VE: Writing – Original Draft. SB: Formal Analysis, Supervision, Writing – Review & Editing. FK: Software. All authors approved the final version and agreed to be accountable for all aspects of the work.

# **REFERENCES**

- Hermes HR, Lamarca ICA. Cuidados paliativos: uma abordagem a partir das categorias profissionais de saúde. Ciênc Saúde Coletiva 2013;18(9):2577-88. https://doi.org/10.1590/S1413-81232013000900012
- 2. Cardoso DH, Muniz RM, Schwartz E, Arrieira ICO. Cuidados paliativos na assistência hospitalar: a vivência de uma equipe multiprofissional. Texto Contexto Enferm 2013;22(4):1134-41. https://doi.org/10.1590/S0104-07072013000400032
- Silva AE, Melo VL, Guadalupe MA, Santos TBE dos, Silveira LC da. Perfil dos atendimentos em cuidados paliativos pelo Serviço de Atenção Domiciliar de Divinópolis-MG. Rev Bras Med Fam Comunidade 2023;18(45):3528. https://doi. org/10.5712/rbmfc18(45)3528
- 4. Gabardo JMB, Castilho MJC, Bernardineli AJ, Schuroff HP, Pujals C, Carvalho MDB, et al. Internamento domiciliar via SUS no Brasil, o impacto do programa "Melhor em Casa". Res Soc Dev 2022;11:e36711629177. https://doi.org/10.33448/rsd-v11i6.29177
- 5. Brasil. Ministério da Saúde. Portaria nº 825, de 25 de abril de 2016 [Internet]. Brasília: Ministério da Saúde; 2016 [cited on Dec 01, 2023]. Available at: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2016/prt0825 25 04 2016.html
- 6. Manual de Cuidados Paliativos ANCP Ampliado e atualizado. 2ª ed. São Paulo: ANCP; 2012 [Internet]. [cited on Nov 01, 2022]. Available at: https://dms.ufpel.edu.br/static/bib/manual de cuidados paliativos ancp.pdf
- 7. Academia Nacional de Cuidados Paliativos. Panorama dos Cuidados Paliativos no Brasil [Internet]. São Paulo: ANCP; 2018 [cited on Oct 12, 2022]. Available at: https://paliativo.org.br/wp-content/uploads/2018/10/Panorama-dos-Cuidados-Paliativos-no-Brasil-2018.pdf

- Mattos CW, Derech RD. Cuidados paliativos providos por médicos de família e comunidade na atenção primária à saúde brasileira: Um survey nacional. Rev Bras Med Fam Comunidade 2020;15(42):2094-2094. https://doi.org/10.5712/ rbmfc15(42)2094
- 9. Gryschek G, Pereira EAL, Hidalgo G. Médicos de Família e Cuidados Paliativos: Contribuições ao currículo baseado em competências. Rev Bras Med Fam Comunidade 2020;15(42):2012. https://doi.org/10.5712/rbmfc15(42)2012
- 10. Neves ACDOJ, Seixas CT, Andrade AM, Castro EABD. Atenção domiciliar: perfil assistencial de serviço vinculado a um hospital de ensino. Physis 2019;29(2):e290214. https://doi.org/10.1590/S0103-73312019290214
- 11. Pilatti P, Lagni VB, Picasso MC, Puma K, de Seixas Mestriner RJ, de Oliveira Machado D, et al. Cuidados paliativos oncológicos em um serviço público de atenção domiciliar. Rev Bras Med Fam Comunidade 2017;12(39):1-10. https://doi.org/10.5712/rbmfc12(39)1339
- Ferreira SDSL, Schmitz R, Martins SB, Dos Santos ER. O manejo da dor nos pacientes em cuidados paliativos do Programa Melhor em Casa [Internet]. In: Anais Congresso de Cuidados Paliativos do Mercosul, 3., 2019. Pelotas: Unidade Cuidativa da UFPel, 2019 [cited on Jun 13, 2022]. Available at: https://doity.com.br/anais/iv-congresso-cuidados-paliativos-mercosul-v3-2019/trabalho/93979
- 13. Fripp JC, Facchini LA, Silva SM. Caracterização de um programa de internação domiciliar e cuidados paliativos no Município de Pelotas, Estado do Rio Grande do Sul, Brasil: uma contribuição à atenção integral aos usuários com câncer no Sistema Único de Saúde, SUS. Epidemiol Serv Saúde 2012;21(1):69-78. https://doi.org/10.5123/S1679-49742012000100007.
- 14. Rangel O, Telles C. Tratamento da dor oncológica em cuidados paliativos. Rev HUPE 2012;11(2):32-37. https://doi.org/10.5123/S1679-49742012000100007
- 15. Wiermann E, Del Pilar Estevez Diz M, Caponero R, Sérgio P, Lages M, Záu Serpa De Araujo C, et al. Consenso Brasileiro sobre Manejo da Dor Relacionada ao Câncer Brazilian Cancer Pain Management Consensus Baseado em Reunião de Consenso realizada em São Paulo, Brasil, em 16 de agosto de 2014 [Internet] [cited on Oct 14, 2022]. Available at: https://www.sboc.org.br/sboc-site/revista-sboc/pdfs/38/artigo2.pdf
- 16. Daflon PMN. Papel da Atenção Primária à Saúde na Rede de Atenção aos pacientes que necessitam de cuidados paliativos oncológicos no município do Rio de Janeiro: percepção de gestores. 2020. 82 f. Dissertação (Mestrado Profissional em Saúde da Família) Faculdade de Ciências Médicas, Universidade do Estado do Rio de Janeiro, Rio de Janeiro, 2020 [Internet] [cited on Mar 10, 2023]. Available at: https://profsaude-abrasco.fiocruz.br/sites/default/files/priscila\_moutinho\_daflon dissertação final.pdf
- 17. Fonseca DF, Borsatto AZ, Vaz DC, Santos RDCDJ, Cypriano VDP, Pinto DCDS, et al. Integração com a Atenção Primária à Saúde: Experiência de uma Unidade de Referência em Cuidados Paliativos Oncológicos. Rev Bras Cancerol 2021;67(4):e-011327. https://doi.org/10.32635/2176-9745.RBC.2021v67n4.1327
- 18. Menezes MS, Figueiredo M das GMC. The role of end-of-life palliative sedation: medical and ethical aspects-Review. Rev Bras Anestesiol 2019;69(1):72-7. https://doi.org/10.1016/j.bjane.2018.03.002
- 19. Rosengarten OS, Lamed Y, Zisling T, Feigin A, Jacobs JM. Palliative sedation at home. J Palliat Care 2009;25(1):5-11. https://doi.org/10.1177/082585970902500102
- 20. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat. Care 2013;12(1):1-13. https://doi.org/10.1186/1472-684X-12-7
- 21. Rizzatti SJS., Lampert MA, Brondani CM, Donati L, Hofmann IC, Engel RH. Cuidados paliativos e o preparo para o óbito no domicílio: relato de experiência. Rev Cont Saúde 2013;11(20):865-8. https://doi.org/10.21527/2176-7114.2011.20.865-868