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[Almudena Castaño Reguillo](#)*, [Raquel Sánchez Ruano](#), [Jaime Barrio Cortes](#), [Elena Polentinos-Castro](#)

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Article

Relationship Between the Preferred Place of Death in the Patients' Health Record and the Actual Location of Death in Home Palliative Care: A Retrospective Cohort Study

Almudena Castaño Reguillo ^{1,2,*}, Raquel Sanchez Ruano ^{3,4,5}, Jaime Barrio Cortés ^{6,7},
Elena Polentinos-Castro ^{8,9,10} and ESAPD Espronceda Collaborative Group

- ¹ Family and Community Medicine. CS Los Angeles. Madrid Health Service (SERMAS)
- ² Doctoral Program in Epidemiology and Public Health (Interuniversity), Rey Juan Carlos University, Madrid, Spain
- ³ Research Unit, Primary Care Assistance Management, Madrid Health Service, Madrid, Spain
- ⁴ Research Network on Chronicity, Primary Care and Health Promotion -RICAPPS-(RICORS), ISCIII, Madrid, Spain
- ⁵ Gregorio Marañón Health Research Institute, Madrid Health Service, Madrid, Spain. Foundation for Biosanitary Research and Innovation in Primary Care of the Community of Madrid (FIIBAP), Madrid, Spain
- ⁶ Foundation for Research and Biosanitary Innovation in Primary Care, Avenida de la Reina Victoria, 21, 28003 Madrid, Spain
- ⁷ HM Faculty of Health Sciences, University Camilo José Cela, Castillo de Alarcón, 49, 28692 Madrid, Spain. HM Hospitals Research Institute, 28692 Madrid, Spain
- ⁸ Primary Care Assistance Management Research Unit, Madrid Health Service, Madrid, Spain
- ⁹ Research Network on Chronicity, Primary Care and Health Promotion -RICAPPS- (RICORS). ISC III. Spain. Gregorio Marañón Health Research Institute, Madrid Health Service, Madrid, Spain
- ¹⁰ Department of Medical Specialties and Public Health, Rey Juan Carlos University, Alcorcón, Madrid, Spain
- * Correspondence: almudenacasre@hotmail.com

Abstract

Background: Dying in the preferred place is considered an indicator of quality of end-of-life care. Advance care planning and home palliative care may increase the likelihood of dying at home. This study aimed to assess whether recording patients' preferred place of care or death is associated with the actual place of death among patients followed by home palliative care teams. **Methods:** We conducted a retrospective observational study including adult patients who died in 2022 and were followed by a home palliative care team in Madrid, Spain. Sociodemographic and clinical variables, recorded preferred place of care or death, and actual place of death were extracted from electronic health records. Associations were analysed using bivariate tests and multivariable logistic regression. **Results:** A total of 464 patients were included (53% women; mean age 80.8 years). Overall, 82.5% died at home. A preferred place of care or death was recorded for 64% of patients; among them, 97.6% expressed a preference for home, and 89% of these patients died at home. In the multivariable analysis, older age and female sex were independently associated with death at home. Recording a preferred place of care or death was not independently associated with the place of death. **Conclusions:** Most patients followed by home palliative care teams died at home. Older age and female sex were associated with a higher probability of home death. Although most patients with a recorded preference for home died at home, recording preferences alone was not independently associated with the place of death. Systematic documentation of preferences may support advance care planning and patient-centred decision-making.

Keywords: end-of-life care; terminal care; death; home patient-centered care; hospice; hospital; palliative care; place of death; preferences; advanced care planning

1. Background

Most people express a preference to die at home when facing advanced or life-limiting illness [1–3]. However, in Spain and in other countries with similar socioeconomic characteristics, most deaths still occur in hospitals or institutional settings, while only about one third take place at home [4–8]. Dying in the preferred place is considered an indicator of quality of end-of-life care and a key component of a “good death” [2,3,9,10].

Previous studies have shown that the probability of dying at home is influenced by multiple clinical and social factors, including older age [5,7,8,14], the presence of a primary caregiver [11,13,15], functional decline [10,11,14], socioeconomic status [16,17], rural residence [7,15], marital status [5,7] and sex, although findings regarding sex remain inconsistent [6,7,14,18].

Home palliative care (HPC) services play a central role in enabling patients to remain at home at the end of life. Their involvement has been associated with fewer emergency department visits and a lower probability of hospital death [4,11,17,19,20]. Similarly, primary care follow-up and the availability of social and healthcare resources increase the likelihood of dying at home [14,15,21,22].

In this context, advance care planning (ACP) is particularly relevant. ACP is defined as a process that supports patients in understanding and sharing their values, goals and preferences regarding future medical care [25]. ACP has been associated with reduced hospital deaths and increased home deaths [20,26]. One of its most accessible components in routine practice is the documentation of the patient’s preferred place of death.

Although several studies have examined factors associated with place of death, few have specifically evaluated whether recording the preferred place of death in the clinical record is associated with the actual place of death among patients receiving home palliative care [27]. This represents an important gap, as documenting preferences may reflect the existence of ACP discussions and may facilitate shared decision-making and coordinated care [28].

The primary objective of this study was to analyse whether the explicit recording of the preferred place of care or death in patients followed by a home palliative care team was associated with a greater probability of dying in the preferred place. Secondary objectives were to explore other sociodemographic and clinical factors associated with the place of death.

2. Methods

2.1. Study Design and Setting

We conducted a retrospective observational cohort study including patients followed by a home palliative care (HPC) team in Madrid, Spain. The HPC team ESAPD Centro provides home-based palliative care to an urban population of approximately 671,000 inhabitants with diverse socioeconomic characteristics [29].

Home palliative care in Madrid is delivered by multidisciplinary teams integrated into the public primary care system, which provides universal coverage and free access at the point of care. These teams work in coordination with primary care services and specialised palliative care units.

2.2. Study Population

The study population comprised all adult patients (≥ 18 years) who were followed by the HPC team and died in 2022. Inclusion criteria were active follow-up by the team and at least one face-to-face home visit.

Patients were excluded if the place of death was not recorded, if death occurred under special circumstances (e.g. euthanasia), or if discrepancies in death-related data could not be resolved.

2.3. Sample Size and Sampling

No sample size calculation was performed because all patients who met the selection criteria ($n = 464$) were included. The flowchart of participant eligibility is shown in Figure 1.

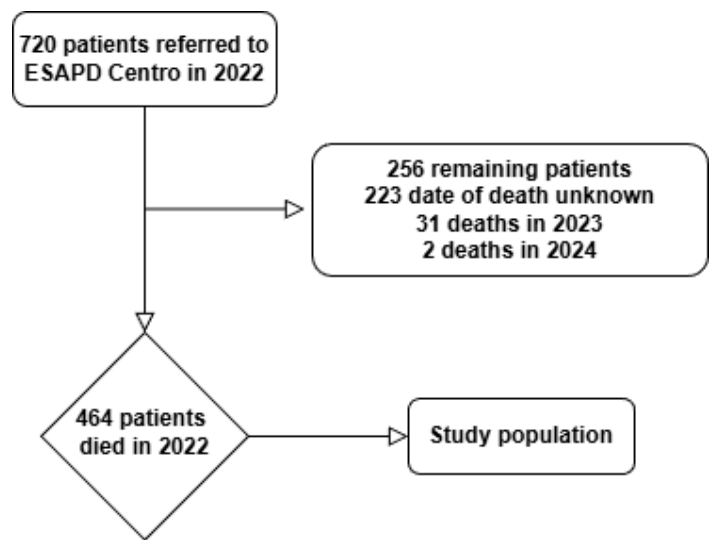


Figure 1. Flowchart of eligible participants.

2.4. Data Source and Variables

Data were extracted from the electronic medical record system (“AP Madrid”), which includes a specific palliative care protocol completed by healthcare professionals during patient assessment and follow-up. Sociodemographic variables (sex, age, presence of a primary caregiver), clinical variables (type of advanced disease: oncological or non-oncological), and information related to death (patients’ and their families’ preferred place of death and care (home/health centre), changes in these preferences, and actual place of death (home/health centre)) were extracted.

The main exposure variable was the recorded preferred place of care or death. The primary outcome was the actual place of death. Although preferred place of care and preferred place of death are conceptually distinct, they were analysed together due to the structure of routine clinical records, which frequently combine both concepts.

2.5. Statistical Analysis

Continuous variables are expressed as medians and interquartile ranges (IQRs, 25–75%) or means and standard deviations SDs. Categorical data are expressed as absolute and relative frequencies. A descriptive analysis of the sociodemographic and clinical characteristics and place of death of the study population was performed, with relative and absolute frequencies and measures of central tendency and dispersion reported according to the characteristics of the variables. Bivariate analyses were performed to assess associations between the place of death and sociodemographic, clinical and preference-related variables, using the chi-square test for categorical variables and Student’s t test for continuous variables.

Variables that showed a statistically significant association in bivariate analyses or were considered clinically relevant were entered into a multivariable logistic regression model to identify factors independently associated with death at home. Results are reported as odds ratios (ORs) with 95% confidence intervals (95% CI).

Statistical significance was defined as $p < 0.05$. All analyses were performed using IBM SPSS Statistics version 26.0.

3. Results

3.1. Patient Characteristics

A total of 464 people were included; 53% were women, the mean age was 80.8 years (SD ± 13.0). The median duration of follow-up by the HPC team was 20 days (IQR 7–57), and 24.1% of patients had a recorded primary caregiver.

Regarding diagnosis, 61% of patients had oncological disease, most frequently digestive system cancers. Among non-oncological conditions, heart failure was the most common diagnosis (Appendix A).

Overall, 82.5% of patients died at home, 14.1% in hospital and 3.4% in a mid-stay palliative care unit.

A preferred place of death was recorded for 24.6% of patients, whereas a preferred place of care or death was recorded for 64.0%. Among patients with a recorded preference, 97.6% expressed a preference for home and 2.4% for a non-home setting. Of those who preferred home, 89.0% died at home.

Baseline characteristics and preferred and actual places of death are shown in Table 1.

Table 1. Baseline characteristics of the study population (n = 464). Abbreviations: SD, standard deviation; IQR, interquartile range.

		n = 464	%
Sex (Female)		246	53
Had a caregiver (Yes)		112	24.1
Age (years, SD)		80.8±13.0	
HPC follow-up duration (days, IQR)		20 (7-57)	
Place of death	Home	383	82.5
	Hospital	65	14.1
	Mid-stay Palliative Care Unit	16	3.4
	Not recorded	350	75.4
Preferred place of death	Home	109	23.5
	Hospital	5	1.1
	Not recorded	167	36
Preferred place of care or death	Home	290	62.5
	Hospital	5	1.1
	Mid-stay Palliative Care Unit	2	0.4
	Not recorded	167	36

3.2. Factors Associated with the Place of Death

Patients who died at home were older than those who died in institutional settings (mean difference: 3,8 years; p < 0,05). Women died at home more frequently than men (86,2% vs 78,4%, p < 0,05) (Table 2.)

Home death occurred in 87,2% of non-oncological patients and in 79,6% of oncological patients (p < 0,05). No significant differences were observed according to the presence of a primary caregiver.

The association between having a recorded preference for home and the actual place of death was not statistically significant (p = 0.87).

Table 2. Factors associated with death at home (bivariate analysis). p-values from chi-square test or Student’s t-test as appropriate.

Variable	Home death n (%)	Non-home death n (%)	p-value
Female sex	212 (86.2%)	34 (13.8%)	<0.05
Male sex	171 (78.4%)	47 (21.6%)	<0.05
Age (mean, years)	82.1	78.3	<0.05
Non-oncological disease	156 (87.2%)	23 (12.8%)	<0.05
Oncological disease	227 (79.6%)	58 (20.4%)	<0.05
Primary caregiver	Not significant	Not significant	>0.05
Preference for home recorded	Not significant	Not significant	0.87

3.3. Factors Associated with Recording Preferences

Women were more likely than men to have a recorded preferred place of death (26.4% vs 22.5%). Additionally, a greater percentage of women (58.72%) who desired to die at home did so, but the difference with the corresponding percentage of men was not statistically significant ($p = 0.087$). Among patients who expressed a preference for home, women achieved this preference more frequently than men (53.1% vs 46.9%, $p = 0.042$).

A higher proportion of oncological patients had a recorded preference compared with non-oncological patients (58.8% vs 41.2%). There were no relevant differences in the preferred place of death according to the specific type of pathology.

3.4. Multivariable Analysis

In the multivariable logistic regression model, older age (OR 1.02; 95% CI 1.00–1.04; $p = 0.026$) and female sex (OR 0.60; 95% CI 0.37–0.98; $p = 0.042$) were independently associated with death at home (Table 3).

Recording a preferred place of care or death was not independently associated with the place of death after adjustment.

Table 3. Multivariable logistic regression for death at home. Abbreviations: OR, odds ratio; CI, confidence interval.

Variable	OR	95% CI	p-value
Age (per year)	1.02	1.00–1.04	0.026
Female sex	0.60	0.37–0.98	0.042
Oncological disease	Not significant	—	>0.05
Preference recorded	Not significant	—	>0.05

4. Discussion

This study examined factors associated with place of death among patients followed by a HPC team in an urban area of Madrid. Most patients died at home, and older age and female sex were independently associated with home death. Although most patients with a recorded preference for home ultimately died at home, recording preferences was not independently associated with the place of death after adjustment.

The high proportion of home deaths observed in our study exceeds that reported in most population-based studies [4–8]. This likely reflects the characteristics of patients referred to HPC teams, for whom a decision regarding end-of-life care location has often already been made prior to referral. In addition, access to specialised HPC and coordinated primary care may facilitate symptom control and prevent unnecessary hospital admissions.

Older age was associated with a greater probability of dying at home, consistent with previous studies [5,7,8,14]. This may be explained by greater acceptance by patients, families and healthcare providers of the appropriateness of focusing on comfort-oriented care rather than hospital transfer. Disease trajectories may also be more predictable in older patients, facilitating earlier palliative care involvement. Previous studies have shown that elderly patients with advanced illnesses prefer to die at home since they are closer to their loved ones, which alleviates the burden of symptomatology without increasing the burden on the caregiver, particularly when they are accompanied by services such as those provided by HPC teams and primary care doctors [30].

In our cohort, women were more likely to die at home than men. Findings regarding sex differences in place of death are inconsistent in the literature [6,7,14,18], although some studies have shown that, similar to our findings, more women die at home than men do [20]. Possible explanations include greater involvement of women in ACP discussions and avoiding hospitalization. Moreover, notably, women generally die at an older age, which may influence care decisions [8,20]. However, for a patient to die at home, the presence of an effective caregiver is necessary; owing to cultural influences, it is more likely that this role is played by a woman (wife, daughter, or sister), and thus men are more likely to have caregivers. However, information on caregiver characteristics was not available in our study and should be addressed in future research, since the sex of the caregiver could play an important role in the place of death [31]. To this end, we also note that our study was conducted primarily in an urban environment in one of the largest cities in Europe, and it could be interesting to conduct further studies addressing this variable [32].

We did not observe a significant association between the presence of a recorded caregiver and the place of death, contrary to previous studies [11,13,15]. This may be due to under-recording or misclassification of this variable in routine clinical practice. However, this result may reflect a recording bias for this variable; in previously mentioned studies [31, 32], having a primary caregiver positively influenced dying in the patient's desired location.

Although ACP has been associated with increased home death [20,26], our results suggest that recording preferences alone is insufficient to determine the place of death. Documentation may be a marker of ongoing discussions rather than a causal factor. Achieving the preferred place of death likely requires adequate resources, caregiver support and coordinated care. Likewise, it is important to expand the knowledge on how cultural differences can influence both the place of death and the preferences of each person, as well as the predisposition to start ACP [3].

This study has several limitations. First, this study is limited by its retrospective design and the use of routinely collected data, which may lead to information bias and under-recording. Consequently, depending on the professional, certain information may be underreported. On the other hand, patients who prefer to die at home may state as such more clearly; therefore, there is an increased probability that it will be included in the clinical history, thus allowing their desires to be fulfilled more easily. Thus, variability in the quality of the records—in terms of whether the patient has expressed his or her preference to the team or to his or her family or whether there has been a change in that preference and the professional has not recorded it—can be expected. In summary, the quality of the information available to us may be limited, resulting in information bias.

Second, caregiver-related variables and socioeconomic factors were not included, which may have influenced the place of death. Also, the study was conducted in a single urban area, which may limit generalisability. Although our study focused on a highly urbanized area and was not multicentric, it presents a wide range of deprivation indices as measured through the MEDEA index [29], as it included areas with very different levels of education, country of origin or socioeconomic level, providing greater strength to the data collected [5, 7, 15]. These unmeasured variables may partly explain the high rate of home deaths observed, independently of preference recording.

A major strength of this study is the use of real-world data from a large and heterogeneous population, enhancing external validity for similar urban settings. Similarly, the study has a large and heterogeneous sample size that, by exhibiting a relatively balanced distribution between the groups, supports its external validity and favours its translation to other care contexts.

In clinical practice, systematically exploring and documenting patients' preferences regarding place of care and death may support patient-centred decision-making and help align care with patients' values. However, achieving the preferred place of death likely requires not only documentation but also adequate resources, caregiver support and coordinated care.

5. Conclusion

This study evaluated the factors that were associated with fulfilling the preferences for place of death. Older age and female sex were independently associated with a higher probability of home death. Although most patients who expressed a preference for home achieved this outcome, recording the preferred place of care or death was not independently associated with the place of death.

Systematically exploring and documenting patients' preferences regarding place of care and death remains an important component of ACP and patient-centred care, but must be accompanied by sufficient resources and coordinates support to ensure that preferences can be fulfilled. Taking into account the preferences of patients allows the people directly involved in their care to establish appropriate therapeutic objectives and avoid aggressive measures or treatments and unnecessary expenses; thus, the patient is able to participate in decision-making about their own health.

Author Contributions: ACR: conceptualization, design, data interpretation, writing of the work. RSR: substantial revision of the text. JBC: substantial revision of the text. EPC: methodology, data analysis, substantial revision of the text. ESAPD Espronceda Collaborative Group: data collection and article review. All the authors read and approved the final manuscript.

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Institutional Review Board Statement: The present study was approved by the Drug Research Ethics Committee of the University Hospital of La Princesa on 6 October 2023 (CEIm act 18/23, approval code: 5357) and by the Local Research Commission Center of Primary Care Management of SERMAS on 11 January 2024 (act 1/2024, committee code: 20230002). The data analysed in this investigation were collected by the professionals who had treated these patients and were anonymized to ensure patient confidentiality.

Informed Consent Statement: Not applicable. This study used secondary data extracted from the AP Madrid electronic medical record system, which includes anonymized clinical and sociodemographic information of patients who received home palliative care. As the data was collected as part of routine clinical care and not through direct participant engagement in this study, no informed consent was required. The data were anonymized to ensure confidentiality and privacy, and all analyses were conducted in accordance with ethical standards.

Data Availability Statement: The datasets generated and analysed during the current study are not publicly available due to privacy restrictions, but can be obtained upon reasonable request.

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Conflicts of Interest: The authors declare no conflict of interest.

List of Abbreviations

AECC	Asociación Española Contra el Cáncer (Spanish Association Against Cancer)
PC	Palliative care
HPC	Home palliative care
AD	Alzheimer's disease
ALS	Amyotrophic lateral sclerosis
MS	Multiple sclerosis
COPD	Chronic obstructive pulmonary disease
ACP	Advance care planning
SERMAS	Servicio Madrileño de Salud (Madrid Health Service)
MSPCU	Mid-stay palliative care units
APCU	Acute palliative care hospitalization unit

Appendix A. Clinical Characteristics of the Participants

Group	Subgroup	% in subgroup	Pathology	N	%
Nononcological	Neurodegenerative diseases	20.7	Alzheimer's disease (AD)	8	1.72
			Parkinson's disease	3	0.65
			Dementia with Lewy bodies	1	0.22
			Prion disease	1	0.22
			Amyotrophic lateral sclerosis (ALS)	5	1.08
			Multiple sclerosis (MS)	2	0.43
			Other dementias/neurodegenerative diseases	17	3.66
	Respiratory diseases	17.8	Chronic obstructive pulmonary disease (COPD)	15	3.23
			Interstitial lung diseases	6	1.29
			Other chronic respiratory diseases	11	2.37
	Organ deficiencies	28.5	Heart failure	34	7.33
			Chronic kidney disease	13	2.8
			Hepatic insufficiency	4	0.86
	Vascular diseases	5.6	Stroke	7	1.51
			Other	3	0.65
	Other nononcological diseases	27.4	Advanced geriatric disease	31	6.68
			Other	18	3.88
Oncological	Digestive	36.9	Colon cancer	37	7.97
			Rectal cancer	13	2.8
			Pancreatic cancer	20	4.31
			Cholangiocarcinoma	5	1.08
			Hepatocellular carcinoma	8	1.72

			Oesophageal cancer	2	0.43
			Gastric cancer	1	0.22
			Other digestive cancers	19	4.09
Respiratory	17.9		Bronchus and lung cancer	51	10.9
				9	
Gynaecological	15.8		Breast cancer	24	5.17
			Ovarian cancer	12	2.59
			Endometrial, cervical, uterine body cancers	8	1.72
			Vulvar cancer	1	0.22
Genitourinary	12.9		Bladder cancer	14	3.02
			Prostate cancer	13	2.8
			Renal cancer	9	1.94
			Other genitourinary cancers	1	0.22
Haematological	3.2		Multiple myeloma	4	0.86
			Lymphomas	3	0.65
			Acute myeloid leukaemia	2	0.43
Skin and appendages	2.8		Melanoma	7	1.51
			Basal cell carcinoma	1	0.22
Head and neck	2.5		Face, head and neck cancers	7	1.51
Central nervous system	1.4		Glioblastoma multiforme	4	0.86
Bone and soft tissue	0.7		Liposarcoma	2	0.43
Other oncological diseases	5.9		Other cancers	17	3.66
Total				464	100

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