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Palliative Care Burden and Specialist Service Utilization for Individuals with Cardiovascular disease: A National Population-Based Study

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Palliative Care Burden and Specialist Service Utilization for Individuals with Cardiovascular disease: A National Population-Based Study

Abstract

Background: cardiovascular disease is a major cause of death globally. In advanced stages, patients with cardiovascular disease often require palliative care due to reduced health-related quality of life from physical, psychological, and spiritual symptoms, along with physical disability.

Objectives: To investigate 1) the symptom and function burden of patients with cardiovascular disease on their first admission to specialist palliative care services and 2) how these care burdens, and other clinical characteristics affected patients' utilization of community-based versus inpatient services.

Design: An observational study using point-of-care outcomes sourced from the Australian Palliative Care Outcomes and Collaboration (PCOC).

Settings: Community-based and inpatient Specialist palliative care services across Australia registered in the Palliative Care Outcomes Collaboration.

Participants: Patients who required specialist palliative care principally for cardiovascular disease, and whose death occurred between 1 January 2013 and 31 December 2022.

Methods: Five validated clinical instruments were used to collect point-of-care outcomes on each individual's function (Resource Utilisation Groups - Activities of Daily Living & Australia-modified Karnofsky Performance Status), symptom distress (Symptoms Assessment Scale & Palliative Care Problem Severity Score) and other clinical characteristics (Palliative Care Phases). Multivariable logistic regression was applied to evaluate how patients' functional and symptom burden influenced their use of inpatient versus community-based palliative care services.

Results: Our analysis included 17,002 patients with cardiovascular disease, with 7,539 (44.3%) receiving community palliative care services and 9,463 (55.7%) accessing inpatient palliative care services. Upon admission to palliative care services, patients often exhibit significant physical functional impairments and substantial symptom

burdens, particularly related to fatigue and breathing difficulties. In comparison, patients accessing inpatient services tended to have greater functional impairment but commonly reported lower symptom burdens ($p < 0.001$). Our analysis indicated that greater functional impairment, poorer overall health condition, and hospital referrals were predictors of inpatient services use. Surprisingly, higher levels of symptom distress and challenges in symptom management were associated with a decreased likelihood of utilizing inpatient services compared to community-based services.

Conclusion: Patients with cardiovascular disease frequently require support to manage decreased functional abilities, as well as symptoms like fatigue and breathing difficulties. With greater investment in community-based supportive services and a skilled palliative care workforce, more individuals with advanced cardiovascular disease could potentially receive palliative care in community settings.

Strengths and limitations of this study

- This study is the first large-scale, national investigation in Australia that specifically focuses on the clinical characteristics and care needs of patients with cardiovascular disease (CVD) receiving palliative care.
- It provides a comprehensive examination of the associations between clinical characteristics and the utilization of different types of palliative care services.
- The multivariate models did not include other significant clinical factors (e.g., the need for management of edema and cognitive impairment) or social factors, which could influence the use of various types of palliative care services.
- The higher rate of proxy-reported assessments in the inpatient group, as compared to the community group, may have introduced discrepancies that affect the reliability of the data.

63 Introduction

64 Cardiovascular disease (CVD) is a leading cause of death in Australia and worldwide.¹
65 Individuals with severe stages of CVD often experience a diminished health-related
66 quality of life due to physical, psychological, and spiritual symptoms, as well as physical
67 disability.²⁻⁴

68 Palliative care is a patient- and family-centered approach aimed at optimizing patients'
69 quality of life by anticipating, preventing, and treating suffering in all its forms.⁵ It is
70 recommended for integration into the management of all chronic illnesses and can
71 complement curative treatments.^{2, 6-8} Robust evidence demonstrates that palliative care
72 significantly enhances patient satisfaction and overall quality of life.^{2, 9-11} palliative care
73 should be accessible in all settings where patients require it, with a primary focus on both
74 community and hospital environments.^{5, 6, 12} Community-based and inpatient palliative
75 care differ in their structure and processes, yet both are essential for delivering
76 comprehensive care.¹³⁻¹⁵ Different types of palliative care are integral to ensuring patients
77 receive the necessary support tailored to their specific needs and circumstances.^{5, 15}

78 Despite the significant disease burden similar to that of cancer patients, palliative care is
79 currently underutilized in patients with advanced CVD.^{3, 16, 17} Addressing this disparity
80 and ensuring that CVD patients receive 'the right care, in the right place, at the right time'
81 presents a significant challenge in optimizing palliative care for this group.^{17, 18} Previous
82 research has predominantly focused on understanding the palliative care needs of this
83 patient group.¹⁹ However, there is a notable gap in exploring their patterns of palliative
84 care utilization, particularly how clinical characteristics and specific palliative care needs
85 influence the use of different types of palliative care services. This area warrants further

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3 86 investigation to better tailor palliative care services to the unique requirements of this
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5 87 group.
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8 88 Therefore, our study used a nationwide sample of deceased cardiovascular patients to
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10 89 investigate: 1) patients' symptom and functional burden on their first admission to
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12 90 specialist palliative care services, and 2) how patients' symptom and functional burden
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14 91 and other clinical characteristics affected their utilization of community-based versus
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16 92 inpatient palliative care services. Our findings have the potential to guide policy
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18 93 development, optimize resource allocation, and enhance the training of healthcare
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20 94 professionals to improve the delivery of palliative care services tailored to the needs of
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22 95 patients with cardiovascular diseases.
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27 96 **Materials and METHODS**

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30 97 *Data Source*

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33 98 Our study utilized anonymized patient outcome data from the Australian Palliative Care
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35 99 Outcomes Collaboration (PCOC), a national, government-funded initiative by the
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37 100 Australian Health Services Research Institute.²⁰ The PCOC aims to enhance the quality of
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39 101 palliative care through a systematic process involving routine assessments, measurement,
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41 102 reporting of patient outcomes, and benchmarking. The palliative care services registered
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43 103 with PCOC assess clinical outcomes of their patients using validated and standardized
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45 104 tools (refer to data collection tools below).
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50 105 Inpatient palliative care services conduct these assessments at admission, every 24 hours
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52 106 thereafter and at discharge to guide patient care. Community-based palliative services
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54 107 perform assessments on admission, during each subsequent patient contact and at
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discharge. These assessments results are submitted to PCOC biannually and PCOC processes these data for validation and quality assurance. Based on this data, the PCOC national office generates biannual reports on clinical performance for each participating service. These services can then benchmark their performance against national averages and industry-agreed standards, fostering an environment of continuous improvement in palliative care.

Study Population and Settings

This study included individuals who satisfied the following criteria: (1) accessed specialist palliative care from Australian services registered with PCOC; (2) had CVD identified as the primary life-limiting condition necessitating palliative care; (3) their initial palliative care episode and death occurred between January 1, 2013, and December 31, 2022. The study specifically focused on the initial assessment conducted at the admission to the first episode of palliative care for each patient. An 'episode of care' is defined as a continuous period of care provided to a patient in a single care setting. The study examined patients from two categories of episodes: those in community-based settings and those in inpatient facilities. 'Inpatient episodes' document one of the overnight admitted options: designated palliative care beds or non-designated palliative care beds. 'Community episodes' document one of the community options: private residences or residential aged care facilities.

Variables and Data Collection Tools

The palliative care services registered with PCOC evaluate patients' clinical outcomes using five standardized and validated tools:

130 PCOC Symptom Assessment Scale (PCOC SAS): An 11-point scale ranging from 0
131 (absent) to 10 (worst possible), used to measure distress from common symptoms
132 requiring palliative care, such as sleep difficulties, appetite issues, nausea, bowel
133 problems, breathing difficulties, fatigue, and pain.²¹ This assessment is preferably done
134 by patients; however, proxy assessment is also acceptable when direct patient reporting is
135 not feasible.

136 Palliative Care Problem Severity Score (PCPSS): Clinicians use this tool to assess the
137 global severity and complexity of patients' palliative care problems, including pain, other
138 symptoms, and psychological/spiritual and family/carer issues.²⁰ PCPSS is a 4-point scale
139 where 0 indicates absence and 3 signifies severe problems.

140 Resource Utilization Groups–Activities of Daily Living (RUG-ADL): This tool evaluates
141 patients' functional dependency levels in activities such as eating, toileting, bed mobility,
142 and transfers. Eating was assessed on a 3-point scale (1 for independent or supervision
143 only, 3 for total dependence/tube fed), and the other activities on a 4-point scale (1/2 for
144 independent and monitor, 5 for assistance from two or more persons).²²

145 The Australia-modified Karnofsky Performance Status (AKPS) Scale evaluates a
146 patient's performance in terms of activity, work, and self-care. Clinicians assign a single
147 score ranging from 0 to 100, based on their observations of the patient's ability to perform
148 typical tasks related to these dimensions. A score of 100 represents normal physical
149 abilities with no signs of disease, while lower scores indicate diminished performance. A
150 score of 0 signifies that the patient has died; however, this score is not used in the PCOC
151 because no further assessments are conducted after a patient's death.²⁰

PCOC Palliative Care Phases: The non-sequential PCOC palliative care phases which describe four distinct, clinically meaningful phases of palliative care (i.e., stable, unstable, deteriorating and terminal) were determined by clinicians based on comprehensive clinical assessments of the patient and their family. The palliative care phase identifies a clinically meaningful period in a patient's condition and served as the foundation for developing palliative care casemix classification. Detailed definitions of each phase can be found in the study by M. Masso et al.²⁰

Other variables included in this study involved demographic data such as sex, age group, country of birth, preferred language, referral source, year of admission, episode length, phase length, Socio-Economic Indexes for Areas (SEIFA), and place of death. SEIFA is a summary measure of social and economic conditions developed by the Australian Bureau of Statistics.²³

Statistical analysis

We described the characteristics of patients, their care episodes and clinical measures using frequency distributions and percentages. Differences between the two groups (inpatient vs. community) were assessed using Pearson's chi-square tests.

To investigate the impact of patients' functional and symptom burden, and other clinical characteristics on the utilization of inpatient versus community palliative care services, we employed multivariable logistic regression models. Significant factors associated with the utilization of different specialist services were identified through backward stepwise regression procedures. Due to substantial multicollinearity among elements of the RUG-ADL scale, only the 'total RUG-ADL' score was included in these stepwise analyses. The

criteria for inclusion and exclusion in the models were set at significance levels of 0.05 and 0.10, respectively. The model's fit was evaluated using the C-index, and P-values for trend were calculated. In our analyses, patients admitted to community-based services served as the reference group.

In our regression analyses, scores on the PCOC SAS, total RUG-ADL, and AKPS were reclassified as categorical variables as follows: PCOC SAS: Since less than 11% of patients had scores greater than 1 on four PCOC SAS symptom scores, the PCOC SAS was categorized into 0=absent (PCOC SAS=0), 1=mild (PCOC SAS=1-3), 2=moderate (PCOC SAS=4-7), and 3=moderate (PCOC SAS=8-10). AKPS: The categorization for AKPS was 1 = normal activity (AKPS=90-100), 2=symptomatic and ambulatory (AKPS = 70-80), 3=occasional assistance required (AKPS =60), 4 = increasingly limited mobility (AKPS = 30-50), 5 = completely bedfast (AKPS = 10 - 20). RUG-ADL: The categories for RUG-ADL were defined as RUG-ADL: 0 = independence or supervision only (total RUG-ADL = 4 - 5), 1 = limited physical assistance (RUG-ADL = 6 - 13), 2 = one assistant plus equipment (RUG-ADL = 14 - 17), 3 = two assistants for full care (RUG-ADL = 18)

We also fitted Kaplan-Meier curves and performed log-rank tests to compare survival time after the first episode of palliative care admission for the two groups.

RESULTS

The characteristics of the study cohort and the community and inpatient episodes are shown in Table 1. The study cohort comprised 17,002 patients, of which 51.8% were male, and 57.1% were aged 85 years or older. Additionally, 61.6% of patients were

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3 196 referred from a hospital, followed by 33.0% referred from a community service. At the
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5 197 time of accessing palliative care, nearly half (49.8%) of patients were in the deteriorating
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11 199 Within this cohort, 44.3% were from community-based palliative care services, and
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13 200 55.7% were from inpatient palliative care services. Compared to the inpatient group,
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15 201 patients in the community group were more likely to be female ($P<0.001$) and older than
16
17 202 85 years ($P<0.001$). A significantly higher proportion of patients in the inpatient group
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19 203 had an episode length of less than one week ($P<0.001$) and were referred from a hospital.
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21 204 Patients in the community group were predominantly assessed as being in the
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23 205 deteriorating (56.9%) and stable (29.5%) phases, while the inpatient group was
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25 206 predominantly assessed as deteriorating (44.1%), followed by terminal (22.6%) and
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27 207 unstable (20.3%) phases ($P<0.001$). The survival curves indicate that the community
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29 208 group had a significantly longer survival time compared to the inpatient group,
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31 209 suggesting that community episodes of palliative care services were initiated much earlier
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35 210 than inpatient episodes.(Figure 1)
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211 Table 1 Sociodemographic and clinical characteristics for people with CVD by episode settings

Characteristics of Patients		All N (%)	Community N (%)	Inpatient N (%)	P values*
Sociodemographic characteristics					
Total number		17,002(100)	7,539(44.3)	9,463(55.7)	
Sex	Male	8,813(51.8)	3,734(49.5)	5,079(53.7)	
	Female	8,179(48.1)	3,798(50.4)	4,381(46.3)	<0.001
	Missing	10(0.1)	7(0.1)	3(0.0)	
Age group	≤74	2581(15.2)	904(12)	1,677(17.7)	
	75-84	4,714(27.7)	1,899(25.2)	2,815(29.7)	
	85-94	7,865(46.3)	3,674(48.7)	4,191(44.3)	<0.001
	≥95	1,838(10.8)	1,058(14.0)	780(8.2)	
	Missing	4(0.0)	4(0.1)	0(0.0)	
SEIFA	1-2	2,232(13.1)	959(12.7)	1,273(13.5)	
	3-4	2470(14.5)	991(13.1)	1,479(15.6)	
	5-6	3360(19.8)	1378(18.3)	1,982(20.9)	<0.001
	7-8	3487(20.5)	1351(17.9)	2,136(22.6)	
	9-10	5350(31.5)	2791(37.0)	2,559(27.0)	

Preferred language	Missing	103(0.6)	69(0.9)	34(0.4)	<0.001
	English	14680(86.3)	6560(87.0)	810(85.8)	
	Non-English	2103(12.4)	848(11.2)	155(13.3)	
	Missing	219(1.3)	131(1.7)	50(0.9)	
	Australia	10154(59.7)	4364(57.9)	50(61.2)	
Country of birth	England	1093(6.4)	529(7.0)	4(6.0)	0.013
	Italy	1160(6.8)	513(6.8)	7(6.8)	
	Greece	531(3.1)	241(3.2)	0(3.1)	
	Else	3723(21.9)	1632(21.6)	91(22.1)	
	Missing	341(2.0)	260(3.4)	8(0.9)	
Characteristics of episode					
Year of admission	2013	1092(6.4)	393(5.2)	69(7.4)	<0.001
	2014	1312(7.7)	523(6.9)	79(8.3)	
	2015	1356(8.0)	626(8.3)	70(7.7)	
	2016	1489(8.8)	655(8.7)	84(8.8)	
	2017	1598(9.4)	670(8.9)	98(9.8)	
	2018	1718(10.1)	799(10.6)	99(9.7)	
	2019	2035(12.0)	981(13.0)	154(11.1)	

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Episode length	2020	2589(15.2)	1278(17.0)	1341(13.9)	
	2021	2663(15.7)	1132(15.0)	1341(16.2)	
	2022	1150(6.8)	482(6.4)	228(7.1)	
	≤1 week	9558(56.2)	2442(32.4)	1346(75.2)	
	1-2 weeks	2222(13.1)	987(13.1)	135(13.1)	
	2-3 weeks	1170(6.9)	685(9.1)	13(5.1)	<0.001
	3-4 weeks	720(4.2)	486(6.4)	14(2.5)	
	>4 weeks	3332(19.6)	2939(39.0)	13(4.2)	
Phase type	Stable	3452(20.3)	2225(29.5)	1327(13.0)	
	Unstable	2274(13.4)	353(4.7)	1321(20.3)	<0.001
	Deteriorating	8462(49.8)	4290(56.9)	472(44.1)	
	Terminal	2814(16.6)	671(8.9)	243(22.6)	
Referral source	Hospital	10469(61.6)	2603(34.5)	786(83.1)	
	Community service	5619(33.0)	4263(56.5)	136(14.3)	<0.001
	Others	774(4.6)	581(7.7)	193(2.0)	
	Missing	140(0.8)	92(1.2)	4(0.5)	

Abbreviations: SEIFA: Socio-Economic Indexes for Areas (scores 1-10).

* Comparisons between the two groups were conducted using Pearson’s chi-square tests. Missing data entries were not accounted for in the analyses.

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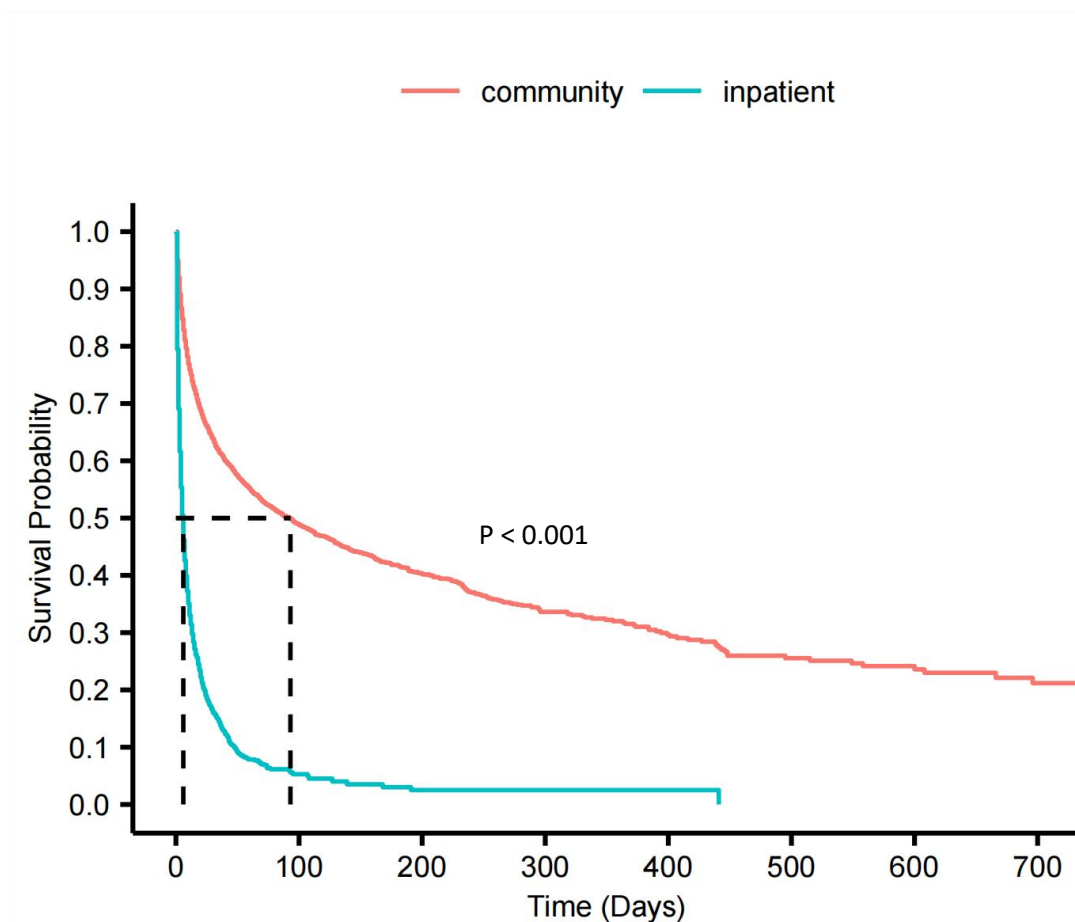


Figure 1. Survival curves for patients with CVD referred to inpatient versus community palliative care services. Comparison between the two groups was performed using log-rank tests.

Clinical outcome measures for both groups of patients are shown in Table 2. Overall, patients in both groups exhibited high levels of functional and performance impairment, with one-third being completely bedfast (AKPS score = 10-20) and requiring two assistants for full care (Total RUG-ADL scores= 18). Significant differences in function and performance impairment were observed between the two groups. The proportions of patients in the inpatient group requiring two assistants for full care (43.30% vs. 20.25%) or being completely bedfast (46.91% vs. 20.59%) were more than double those of the community group ($P < 0.001$). Regarding the SAS assessments, severe levels of distress were uncommon across all symptoms. Fatigue and breathing problems were the top two

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227 sources of distress, causing moderate and severe levels of distress in more than one-third
228 of patients. In terms of assessments for palliative care problems (PCPSS), approximately
229 one-third of patients experienced moderate and severe levels of problems related to other
230 symptoms and family issues, compared to nearly 15% for psychological problems and
231 pain. A significant disparity in symptom burden was observed between the two groups.
232 Most often, the inpatient group had higher proportions of absent category, fewer mild
233 category, and equivalent moderate category across all symptom assessments ($P < 0.001$
234 for each). The differences in the severe category between the two groups were not
235 evident due to the small proportion of this category for the both groups.

242 Table 2 Clinical measure outcomes for patients with CVD by episode settings

Characteristics of Patients		All N (%)	Community N (%)	Inpatient N (%)	P values*
Sociodemographic characteristics					
Sex	Total number	17,002(100)	7,539(44.3)	9,463(55.7)	
	Male	8,813(51.8)	3,734(49.5)	5,079(53.7)	
	Female	8,179(48.1)	3,798(50.4)	4,381(46.3)	<0.001
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	≥95	1,838(10.8)	1,058(14.0)	780(8.2)	
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	9-10	5350(31.5)	2791(37.0)	2,559(27.0)	

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Preferred language	Missing	103(0.6)	69(0.9)	34(0.4)	<0.001
	English	14680(86.3)	6560(87.0)	810(85.8)	
	Non-English	2103(12.4)	848(11.2)	155(13.3)	
	Missing	219(1.3)	131(1.7)	50(0.9)	
	Australia	10154(59.7)	4364(57.9)	50(61.2)	
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	Else	3723(21.9)	1632(21.6)	91(22.1)	
	Missing	341(2.0)	260(3.4)	8(0.9)	
Characteristics of episode					
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	2014	1312(7.7)	523(6.9)	79(8.3)	
	2015	1356(8.0)	626(8.3)	70(7.7)	
	2016	1489(8.8)	655(8.7)	84(8.8)	
	2017	1598(9.4)	670(8.9)	98(9.8)	
	2018	1718(10.1)	799(10.6)	99(9.7)	
	2019	2035(12.0)	981(13.0)	154(11.1)	

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Episode length	2020	2589(15.2)	1278(17.0)	1341(13.9)	
	2021	2663(15.7)	1132(15.0)	1341(16.2)	
	2022	1150(6.8)	482(6.4)	482(7.1)	
	≤1 week	9558(56.2)	2442(32.4)	2442(75.2)	
	1-2 weeks	2222(13.1)	987(13.1)	987(13.1)	
	2-3 weeks	1170(6.9)	685(9.1)	685(5.1)	<0.001
	3-4 weeks	720(4.2)	486(6.4)	486(2.5)	
	>4 weeks	3332(19.6)	2939(39.0)	2939(4.2)	
Phase type	Stable	3452(20.3)	2225(29.5)	2225(13.0)	
	Unstable	2274(13.4)	353(4.7)	353(20.3)	
	Deteriorating	8462(49.8)	4290(56.9)	4290(44.1)	<0.001
	Terminal	2814(16.6)	671(8.9)	671(22.6)	
Referral source	Hospital	10469(61.6)	2603(34.5)	2603(83.1)	
	Community service	5619(33.0)	4263(56.5)	4263(14.3)	
	Others	774(4.6)	581(7.7)	581(2.0)	<0.001
	Missing	140(0.8)	92(1.2)	92(0.5)	

Abbreviations: SAS: Symptom Assessment Scale, PCPSS: Palliative Care Problem Severity Score, RUG-ADL: Resource Utilisation Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status,

* Comparisons between two groups were conducted using Pearson's chi-square tests. Missing data entries were not accounted for in the analyses.

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Table 3 presents the adjusted and unadjusted odds ratios (OR) for predictors of inpatient service utilization, using community-based services as the reference group, as determined by a multivariate logistic regression model with a c-statistic of 0.89. Only the adjusted ORs are reported here. Among sociodemographic factors, higher SEIFA scores (adjusted OR ranged from 1.34 to 2.18; $p < 0.001$) are positively associated with utilizing inpatient services. Conversely, female patients (adjusted OR: 0.82; 95% CI: 0.73-0.91; $p < 0.001$), older age (adjusted ORs ranged from 0.52 to 0.81; $p < 0.001$), being born in a country other than Australia (adjusted ORs ranged from 0.58 to 0.88; $p < 0.001$), and years closer to 2022 (adjusted ORs ranged from 0.42 to 0.85; $p < 0.001$) were negatively associated with accessing community-based services. As indicated by the p-values for trend, dose-response associations were observed for the factors of ages ($p < 0.001$), SEIFA ($p < 0.001$) and years of admission ($p < 0.001$).

In terms of clinical characteristics, the most significant factor predicting use of inpatient services was patients being assessed in the unstable phase (adjusted OR: 17.60; 95% CI: 14.15-21.90; $p < 0.001$). Higher scores on RUG-ADL and lower scores on AKPS were linked to increased likelihood of entering inpatient services. Regarding symptom burden, moderate (adjusted OR: 1.20; 95% CI: 1.02-1.40; $p = 0.024$) and severe (adjusted OR: 1.74; 95% CI: 1.32-2.29; $p < 0.001$) breathing problems assessed by PCOC SAS, as well as severe bowel problems (OR: 1.72; 95% CI: 1.03-2.86; $p = 0.038$), positively predicted use of inpatient services compared to absence of these symptoms. Conversely, from mild to moderate levels, symptoms such as insomnia, fatigue, and family issues assessed by PCPSS were consistently associated with lower odds of using inpatient services.

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3 269 Additionally, dose-response associations were identified for all symptom and function-
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5 270 related factors, with a p-value for trend of less than 0.001 for each.
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Table 3 Regression analyses for factors associated with inpatient versus community palliative care				
	Inpatient vs community Unadjusted OR (95%CI, p -value)*	Inpatient vs community Adjusted OR (95%CI, p -value)*	P value for trend	
Sex (ref. male)	0.85(0.80-0.90; <0.001)	0.82(0.73-0.91; <0.001)		
Age group (ref. ≤ 74 years)				
75-84	0.80(0.72-0.88; <0.001)	0.81(0.68-0.96; <0.001)		
85-94	0.62(0.56-0.67; <0.001)	0.69(0.59-0.82; <0.001)	<0.001	
≥95	0.40(0.35-0.45; <0.001)	0.52(0.42-0.65; <0.001)		
Country of birth (ref. Australia)				
England	0.80(0.71-0.91; 0.001)	0.78(0.63-0.97; 0.025)		
Italy	0.95(0.84-1.07; 0.417)	0.87(0.69-1.11; 0.265)		
Greece	0.91(0.76-1.08; 0.275)	0.58(0.42-0.80; 0.001)		
Else	0.97(0.90-1.04; 0.366)	0.88(0.76-1.01; 0.067)		
Preferred language (ref. English)	1.20(1.09-1.31; <0.001)	0.81(0.66-0.99; 0.040)		
SEIFA (ref.1-2)				
3-4	1.45 (1.31-1.60; < 0.001)	1.34 (1.09-1.65; 0.005)		
5-6	1.63 (1.48-1.79; < 0.001)	1.80 (1.49-2.18; < 0.001)	<0.001	
7-8	1.57 (1.44-1.71; <0.001)	2.18 (1.80-2.63; < 0.001)		

9-10	1.72 (1.58-1.88; <0.001)	1.61 (1.35-1.93; <0.001)	
Year of admission (ref. 2013)			
2014	1.28(1.08-1.52; 0.004)	0.85(0.65-1.11; 0.330)	
2015	1.09(0.93-1.28; 0.302)	0.52(0.40-0.68; <0.001)	
2016	0.84(0.72-0.99; 0.033)	0.61(0.47-0.79; <0.001)	
2017	0.92(0.79-1.07; 0.286)	0.70(0.54-0.91; <0.001)	
2018	1.00(0.86-1.17; 0.994)	0.43(0.33-0.56; <0.001)	<0.001
2019	0.83(0.71-0.97; 0.015)	0.42(0.33-0.55; <0.001)	
2020	0.78(0.67-0.90; 0.001)	0.54(0.42-0.70; <0.001)	
2021	0.74(0.64-0.85; <0.001)	0.72(0.56-0.92; 0.009)	
2022	0.98(0.85-1.12; 0.733)	0.81(0.60-1.09; 0.61)	
Referral source (ref. hospital)			
Community service	0.11(0.10-0.11; <0.001)	0.16(0.14-0.18; <0.001)	
Others	0.11(0.09-0.13; <0.001)	0.15(0.12-0.19; <0.001)	
Phase type (ref. stable)			
Unstable	0.17(0.15-0.19; <0.001)	17.60 (14.15-21.90; <0.001)	
Deteriorating	1.70(1.48-1.97; <0.001)	1.28 (1.10-1.48; <0.001)	

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5	Terminal	0.31(0.28-0.34; <0.001)	1.49(1.19-1.86; <0.001)	
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7	RUG Total (ref. independence or			
8	supervision only)			
9				
10	Limited physical assistance	0.12(0.11-0.14; <0.001)	2.53(2.09-3.05; <0.001)	
11				
12	One assistant plus equipment	0.33(0.31-0.36; <0.001)	4.43(3.53-5.58; <0.001)	<0.001
13				
14	Two assistants for full care	0.60(0.55-0.66; <0.001)	6.02(4.62-7.83; <0.001)	
15				
16	AKPS (ref. normal activity)			
17				
18	Symptomatic and ambulatory	1.64(1.27-2.11; <0.001)	1.72(1.15-2.56; <0.001)	
19				
20	Occasional assistance required	2.08(1.63-2.64; <0.001)	2.23(1.50-3.30; <0.001)	
21				<0.001
22	Increasingly limited mobility	5.12(4.05-6.47; <0.001)	4.18(2.80-6.26; <0.001)	
23				
24	Completely bedfast	10.97(8.67-13.88; <0.001)	5.02(3.26-7.74; <0.001)	
25				
26	SAS score for insomnia (ref.absent)			
27				
28	Mild	1.37(1.10-1.70; 0.005)	0.64(0.56-0.74; <0.001)	
29				
30	Moderate	0.55(0.44-0.69; <0.001)	0.58(0.48-0.70; <0.001)	<0.001
31				
32	Severe	0.80(0.63-1.01; 0.064)	0.43(0.29-0.63; <0.001)	
33				
34	SAS score for appetite (ref.absent)			
35				
36	Mild	1.32(1.07-1.63; 0.010)	0.79(0.68-0.90; <0.001)	
37				<0.001
38	Moderate	0.56(0.45-0.69; <0.001)	0.89(0.73-1.08; 0.040)	
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Severe	0.89(0.71-1.12; 0.329)	0.77(0.52-1.14; 0.94)	
SAS score for nausea (ref.absent)			
Mild	0.54(0.48-0.59; <0.001)	0.94(0.79-1.12; 0.90)	
Moderate	0.93(0.79-1.10; 0.408)	1.28(0.97-1.69; 0.76)	<0.001
Severe	1.40(0.94-2.08; 0.096)	1.82(0.93-3.55; 0.82)	
SAS score for bowels (ref.absent)			
Mild	0.68(0.51-0.92; 0.011)	0.61 (0.54-0.71; <0.001)	
Moderate	0.30(0.23-0.41; <0.001)	0.80 (0.65-0.99; 0.36)	<0.001
Severe	0.51(0.37-0.69; <0.001)	1.72 (1.03-2.86; 0.038)	
SAS score for breathing(ref. absent)			
Mild	0.88(0.76-1.02; 0.098)	0.93 (0.81-1.07; 0.322)	
Moderate	0.45(0.39-0.53; <0.001)	1.20 (1.02-1.40; 0.024)	<0.001
Severe	0.65(0.56-0.76; <0.001)	1.74 (1.32-2.29; <0.001)	
SAS score for fatigue (ref. absent)			
Mild	1.60(1.40-1.83; <0.001)	0.72(0.62-0.83; <0.001)	
Moderate	0.54(0.47-0.62; <0.001)	0.73(0.62-0.86; <0.001)	<0.001
Severe	0.75(0.66-0.86; <0.001)	0.65(0.51-0.84; 0.001)	

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SAS score for pain (ref. absent)				
Mild	0.81(0.66-0.99; 0.044)	0.66(0.58-0.74; <0.001)		
Moderate	0.44(0.36-0.54; <0.001)	0.85(0.72-1.01; 0.001)		<0.001
Severe	0.70(0.56-0.86; 0.001)	0.76(0.54-1.07; 0.011)		
PCPSS score for other symptoms (ref. absent)				
Mild	0.55(0.51-0.60; <0.001)	0.82(0.71-0.96; <0.001)		
Moderate	0.62(0.56-0.68; <0.001)	0.91(0.76-1.08; 0.001)		<0.001
Severe	1.11(0.94-1.32; <0.001)	0.97(0.72-1.30; 0.017)		
PCPSS score for family (ref. absent)				
Mild	1.13(0.95-1.34; 0.160)	0.39(0.34-0.45; <0.001)		
Moderate	0.59(0.50-0.69; <0.001)	0.29(0.25-0.34; <0.001)		<0.001
Severe	0.55(0.46-0.65; <0.001)	0.39(0.30-0.52; <0.001)		

Abbreviations: OR: odds ratios, CI: confidence interval, SEIFA: Socio-Economic Indexes for Areas, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: palliative Care Problem Severity Score, SAS: Symptom Assessment Scale, Ref.: reference.

NOTE. Bold indicates significant value $p < 0.05$.

* Unadjusted and adjusted OR values estimated based on univariate and multivariate binary logistic regression models, with using the community group as the reference group. Adjusted models include all variables selected through the forward/backward stepwise procedures; unadjusted models include each specific variable.

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279 **Ethics approval and consent to participate**

280 The PCOC program has been approved by Human Research Ethics Committee (HREC)
281 of the University of Wollongong (HE06/045) and this study was granted waiver of
282 consent by The University of Western Australia HREC (RA/4/1/8365).

284 **DISCUSSION**

285 Our population-based national study examined the symptom and functional burden of
286 CVD patients on their first admission to specialist palliative care services, as well as how
287 these burdens and other clinical characteristics influenced their use of different types of
288 specialist services in Australia. Compared to the community group, the inpatient group
289 exhibited significantly greater dependency and poorer performance, yet reported higher
290 proportions of absent symptom burden and fewer instances of mild symptom burden. An
291 unstable palliative phase, along with greater dependency and poorer performance,
292 predicted the use of inpatient services. Surprisingly, increased symptom burden was often
293 associated with a lower likelihood of utilizing inpatient services compared to community
294 services.

295 Previous studies have extensively documented that fatigue, breathing problems, and
296 functional disabilities are common among palliative care patients with CVD.^{4, 19, 24-26} In
297 our study, patients reported higher levels of distress from fatigue and breathing problems
298 compared to other symptoms. These two symptoms, which are often prevalent and
299 concurrent, pose significant management challenges and are closely linked to impaired
300 quality of life in CVD patients. For instance, a 2019 multicenter study in the U.S.

involving 1,801 palliative care patients with CVD found that the most common symptoms were tiredness (50.3%), anorexia (35.7%), and dyspnea (27.9%).²⁶ Additionally, 38.9% of these patients were bedridden and fully dependent,²⁶ a finding consistent with our study's report of 35.17% of patients being completely bedfast. Beyond symptom management, our study also underscores the importance of addressing family needs and issues, a concern that has been increasingly emphasized in the international palliative care literature.

Our study compared the symptom burden and function impairment between patients referred to community and inpatient services. We discovered that inpatient groups generally reported higher functional disability and lower symptom burden than their community counterparts. The findings regarding function were plausible, given that the inpatient group had a much shorter survival time and a significantly higher proportion of patients in the unstable and terminal stages compared to the community group. However, the findings that inpatient group reported lower symptom burdens were unexpected and inconsistent with our previous studies focusing on the PCOC cohorts of lung cancer,²⁷ dementia²⁸ and stroke.²⁹ One possible explanation relates to referral sources: 83.1% of inpatient group patients were referred from hospitals, while 56.5% of community group patients were referred from community services. It is likely that hospital-referred patients had better-managed symptoms before being referred to palliative care services. Nevertheless, given that palliative care focuses on symptom management, these findings necessitate further exploration of the determinants for patients accessing different types of palliative care services.

Our analyses contributed new insights by identifying the factors that predict the use of inpatient services compared to community-based services. We found that patients from areas with higher social and economic conditions were more likely to use inpatient services. This is likely attributable to the fact that most Australian palliative care workforce are employed in hospital settings in major cities.³⁰ Additionally, our regression model indicated that community services were more widely used in most years between 2014 and 2022 compared to 2013, although the pattern did not persist after 2020, possibly due to the impact of COVID-19. This finding suggests that the efforts of advocacy for increased use of community services has been effective.^{31, 32} Unsurprisingly, referrals from hospitals strongly predict the use of hospital palliative care services, given that many hospitals have a palliative care unit or designated palliative care beds. We also identified that being female and older age were associated with a higher likelihood of using community palliative care services. Further studies are needed to explore the underlying reasons for these associations.

Inpatient services, equipped to provide around-the-clock specialized care, can promptly address patients' complex and urgent symptom management needs.¹⁵ However, our analysis showed that a higher symptom burden was not consistently linked to the use of inpatient services compared to community services. Instead, individuals with a higher symptom burden were more likely to access community services in most situations. These findings indicate that delivery of palliative care service for patients with CVD could benefit from promoting a needs-based care model. However, consensus on need-based palliative care referral criteria in patients with CVD remains lacking.^{18, 33} Elevated clinician-rated scores for family issues were also associated with lower likelihood of

346 using inpatient services in our study. This could be because community healthcare
347 providers, who are more familiar with the family than hospital providers, tend to rate
348 family burden and concerns higher.

349 There was a higher utilization of inpatient services associated with higher levels of
350 dependency and lower functional performance status. Relocating these individuals to an
351 inpatient setting and abruptly altering their living environments may cause increased
352 distress, confusion, and a heightened risk of falls and injuries. For most people in our
353 study without severe or complex symptoms, a more patient-centered management model,
354 based in their usual residence and involving highly trained staff to support families and
355 caregivers, would be optimal. Therefore, a community-based model is suitable for
356 patients with major functional disabilities but not experiencing severe symptoms.

357 Moreover, community-based palliative care services have gained popularity not only
358 because they are more cost-effective compared to inpatient services,³⁴ but also because
359 they facilitate continuity of care by maintaining connections with the patients' regular
360 care providers and enabling patients to stay and die at their preferred place.³⁴ However, it
361 is important to note that home-care arrangements demand significant physical, emotional,
362 and financial commitment from families and caregivers. Many families and caregivers
363 may become fatigued and overwhelmed, or feel unsafe as the patient's condition worsens
364 or if unexpected health changes occur. A common reaction in these situations is to seek
365 institutional care. This aligns with our findings, which indicate increased access to
366 inpatient services for individuals in non-stable (especially unstable) palliative care phases
367 compared to stable phase. Enhanced support for carers and families of people with CVD
368 tends to facilitate longer periods of home care.²⁵

Strengths and limitations

To our knowledge, this is the first large-scale, national study that comprehensively examines the clinical characteristics, care needs, and their associations with the use of different types of palliative care services specifically for people with cardiovascular disease (CVD) in Australia. While the analyses were enhanced by the use of standardized and validated instruments at the point of care, several limitations should be acknowledged. First, some bias may have been introduced by the criteria used for disease classifications in these data. Given that the PCOC only captures the primary diagnosis that necessitates the episode of palliative care, patients included in this study may also had other common comorbidities except for CVD, such as diabetes and dementia. Second, our multivariate models focused on palliative care needs related to symptom and functional burden, but did not include other clinical factors (e.g., need for management of edema and cognitive impairment, etc.) or social factors (e.g., availability of informal carers). These significant and unique characteristics of advanced CVD are important considerations in decisions about the types of services to utilize. Third, the inpatient groups likely had a higher rate of proxy-reported SAS assessments compared to the community groups, given that more patients in the inpatient group were at a later stage of life. The potential discrepancies between patient-reported and proxy-reported outcomes may have introduced bias into our data. Given these limitations, the symptom outcomes reported in this study should be interpreted with caution.

Conclusion

On admission to specialist palliative care services, patients with CVD exhibit high degrees of physical impairment and distress associated with fatigue and breathing

problems. Comparatively, patients entering inpatient services required higher levels of physical assistance but often reported lower levels of symptom burden. Our most notable finding is that elevated symptom distress and difficulties in managing these symptoms unexpectedly predicted a decrease in the utilization of inpatient services compared to community services. Based on these findings, we concluded that there is a significant need to develop a CVD-specific palliative care pathway or referral guidelines to promote needs-based palliative care delivery models. Such a model could enable a larger number of people with advanced CVD to receive care and spend the end of life in their usual accommodations. Promoting these models would require greater investment in supportive services, such as skilled palliative care staff and support for carers, in the community.

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conflicts of interest

None

Reference

(1) Naghavi, M.; Ong, K. L.; Aali, A.; Ababneh, H. S.; Abate, Y. H.; Abbafati, C.; Abbasgholizadeh, R.; Abbasian, M.; Abbasi-Kangevari, M.; Abbastabar, H. Global burden of 288 causes of death and life expectancy decomposition in 204

- countries and territories and 811 subnational locations, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *The Lancet* **2024**, *403* (10440), 2100–2132.
- (2) Hill, L.; Prager Geller, T.; Baruah, R.; Beattie, J. M.; Boyne, J.; de Stoutz, N.; Di Stolfo, G.; Lambrinou, E.; Skibelund, A. K.; Uchmanowicz, I. Integration of a palliative approach into heart failure care: a European Society of Cardiology Heart Failure Association position paper. *European journal of heart failure* **2020**, *22* (12), 2327–2339.
- (3) Ding, J.; Johnson, C. E.; Lee, Y. C.; Gazey, A.; Cook, A. Characteristics of people with dementia vs other conditions on admission to inpatient palliative care. *Journal of the American Geriatrics Society* **2020**, *68* (8), 1825–1833.
- (4) Chan, H. Y.; Doris, S.; Leung, D. Y.; Chan, A. W.; Hui, E. Quality of life and palliative care needs of elderly patients with advanced heart failure. *Journal of geriatric cardiology: JGC* **2016**, *13* (5), 420.
- (5) Radbruch, L.; De Lima, L.; Knaut, F.; Wenk, R.; Ali, Z.; Bhatnagar, S.; Blanchard, C.; Bruera, E.; Buitrago, R.; Burla, C. Redefining palliative care—a new consensus-based definition. *Journal of pain and symptom management* **2020**, *60* (4), 754–764.
- (6) Kaasa, S.; Loge, J. H.; Aapro, M.; Albrecht, T.; Anderson, R.; Bruera, E.; Brunelli, C.; Caraceni, A.; Cervantes, A.; Currow, D. C. Integration of oncology and palliative care: a Lancet Oncology Commission. *The lancet oncology* **2018**, *19* (11), e588–e653.
- (7) Lewin, W. H.; Schaefer, K. G. Integrating palliative care into routine care of patients with heart failure: models for clinical collaboration. *Heart failure reviews* **2017**, *22*, 517–524.
- (8) Puckett, C.; Goodlin, S. J. A modern integration of palliative care into the management of heart failure. *Canadian Journal of Cardiology* **2020**, *36* (7), 1050–1060.
- (9) Quinn, K. L.; Stukel, T.; Stall, N. M.; Huang, A.; Isenberg, S.; Tanuseputro, P.; Goldman, R.; Cram, P.; Kavalieratos, D.; Detsky, A. S. Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: population based matched cohort study. *Bmj* **2020**, *370*.
- (10) Bakitas, M. A.; Dionne-Odom, J. N.; Ejem, D. B.; Wells, R.; Azuero, A.; Stockdill, M. L.; Keebler, K.; Sockwell, E.; Tims, S.; Engler, S. Effect of an early palliative care telehealth intervention vs usual care on patients with heart failure: the ENABLE CHF-PC randomized clinical trial. *JAMA internal medicine* **2020**, *180* (9), 1203–1213.
- (11) Ting, J.; Songer, K.; Bailey, V.; Rotman, C.; Lipsitz, S.; Rosenberg, A. R.; Delgado-Corcoran, C.; Moynihan, K. M. Impact of Subspecialty Pediatric Palliative Care on Children with Heart Disease; A Systematic Review and Meta-analysis. *Pediatric Cardiology* **2024**, 1–15.
- (12) Axelsson, B. The challenge: equal availability to palliative care according to individual need regardless of age, diagnosis, geographical

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location, and care level. *International Journal of Environmental Research and Public Health* **2022**, *19* (7), 4229.

(13) Kamal, A. H. ; Currow, D. C. ; Ritchie, C. S. ; Bull, J. ; Abernethy, A. P. Community-based palliative care: the natural evolution for palliative care delivery in the US. *Journal of pain and symptom management* **2013**, *46* (2), 254–264.

(14) Brereton, L. ; Clark, J. ; Ingleton, C. ; Gardiner, C. ; Preston, L. ; Ryan, T. ; Goyder, E. What do we know about different models of providing palliative care? Findings from a systematic review of reviews. *Palliative medicine* **2017**, *31* (9), 781–797.

(15) Wiencek, C. ; Coyne, P. Palliative care delivery models. In *Seminars in oncology nursing*, 2014; Elsevier: Vol. 30, pp 227–233.

(16) Liu, A. Y. ; O’ Riordan, D. L. ; Marks, A. K. ; Bischoff, K. E. ; Pantilat, S. Z. A comparison of hospitalized patients with heart failure and cancer referred to palliative care. *JAMA network open* **2020**, *3* (2), e200020–e200020.

(17) Quinn, K. L. ; Wegier, P. ; Stukel, T. A. ; Huang, A. ; Bell, C. M. ; Tanuseputro, P. Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA network open* **2021**, *4* (3), e210677–e210677.

(18) Chang, Y. K. ; Kaplan, H. ; Geng, Y. ; Mo, L. ; Philip, J. ; Collins, A. ; Allen, L. A. ; McClung, J. A. ; Denvir, M. A. ; Hui, D. Referral criteria to palliative care for patients with heart failure: a systematic review. *Circulation: Heart Failure* **2020**, *13* (9), e006881.

(19) Quattrone, F. ; Aimo, A. ; Zuccarino, S. ; Morelli, M. S. ; Morfino, P. ; Gioia, A. ; Passino, C. ; Ferrè, F. ; Nuti, S. ; Emdin, M. Unmet needs in end-of-life care for heart failure patients. *International Journal of Cardiology* **2024**, *399*, 131750.

(20) University of Wollongong. *Palliative Care Outcomes Collaboration*. 2024. <https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/> (accessed 2024 June 30).

(21) Daveson, B. A. ; Allingham, S. F. ; Clapham, S. ; Johnson, C. E. ; Currow, D. C. ; Yates, P. ; Eagar, K. The PCOC Symptom Assessment Scale (SAS): A valid measure for daily use at point of care and in palliative care programs. *PLoS One* **2021**, *16* (3), e0247250.

(22) Fries, B. E. ; Schneider, D. P. ; Foley, W. J. ; Gavazzi, M. ; Burke, R. ; Cornelius, E. Refining a case-mix measure for nursing homes: Resource Utilization Groups (RUG-III). *Medical care* **1994**, *32* (7), 668–685.

(23) Australian Bureau of Statistics. *Socio-Economic Indexes for Areas*. 2023. <https://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa> (accessed 2024 June 30).

(24) Gonzalez-Jaramillo, V. ; Maessen, M. ; Luethi, N. ; Guyer, J. ; Hunziker, L. ; Eychmüller, S. ; Zambrano, S. C. Unmet needs in patients with heart failure: the importance of palliative care in a heart failure clinic. *Frontiers in cardiovascular medicine* **2022**, *9*, 866794.

- (25) Ganz, F. D. ; Roeh, K. ; Eid, M. ; Hasin, T. ; Harush, C. ; Gotsman, I. The need for palliative and support care services for heart failure patients in the community. *European Journal of Cardiovascular Nursing* **2021**, *20* (2), 138–146.
- (26) Warraich, H. J. ; Wolf, S. P. ; Mentz, R. J. ; Rogers, J. G. ; Samsa, G. ; Kamal, A. H. Characteristics and trends among patients with cardiovascular disease referred to palliative care. *JAMA Network Open* **2019**, *2* (5), e192375–e192375.
- (27) Ding, J. ; Johnson, C. E. ; Qin, X. ; Ho, S. C. ; Cook, A. Palliative care needs and utilisation of different specialist services in the last days of life for people with lung cancer. *European Journal of Cancer Care* **2021**, *30* (1), e13331.
- (28) Ding, J. ; Cook, A. ; Qin, X. ; Ho, S. C. ; Johnson, C. E. Palliative care needs and utilization of specialist services for people imminently dying with dementia: A national population-based study. *International Journal of Nursing Studies* **2020**, *109*, 103655.
- (29) Liu, H. ; Cook, A. ; Ding, J. ; Lu, H. ; Jiao, J. ; Bai, W. ; Johnson, C. E. Palliative care needs and specialist services post stroke: national population-based study. *BMJ Supportive & Palliative Care* **2024**, *14* (e1), e1422–e1431.
- (30) Australian Institute of Health and Welfare. *Palliative care services in Australia*. 2024. <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce> (accessed 2024 June 30).
- (31) *National Palliative Care Strategy 2018*; 2018. <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>.
- (32) Shadd, J. D. ; Burge, F. ; Stajduhar, K. I. ; Cohen, S. R. ; Kelley, M. L. ; Pesut, B. Defining and measuring a palliative approach in primary care. *Canadian Family Physician* **2013**, *59* (11), 1149–1150.
- (33) Chang, Y. K. ; Allen, L. A. ; McClung, J. A. ; Denvir, M. A. ; Philip, J. ; Mori, M. ; Perez-Cruz, P. ; Cheng, S.-Y. ; Collins, A. ; Hui, D. Criteria for referral of patients with advanced heart failure for specialized palliative care. *Journal of the American College of Cardiology* **2022**, *80* (4), 332–344.
- (34) Spilsbury, K. ; Rosenwax, L. Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life. *BMC palliative care* **2017**, *16*, 1–12.

Palliative Care Burden and Specialist Service Utilization for Individuals with Cardiovascular Disease in Australia: A National Population-Based Observational Study

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Palliative Care Burden and Specialist Service Utilization for Individuals with Cardiovascular Disease in Australia: A National Population-Based Observational Study

Abstract

Background: cardiovascular disease is a major cause of death globally. In advanced stages, patients with cardiovascular disease often require palliative care due to reduced health-related quality of life from physical, psychological, and spiritual symptoms, along with physical disability.

Objectives: To investigate 1) the symptom and function burden of patients with cardiovascular disease on their first admission to specialist palliative care services and 2) how these care burdens, and other clinical characteristics affected patients' utilization of community-based versus inpatient services.

Design: A national population-based observational study using point-of-care outcomes sourced from the Australian Palliative Care Outcomes and Collaboration (PCOC).

Settings: Community-based and inpatient Specialist palliative care services across Australia registered in the Palliative Care Outcomes Collaboration.

Participants: Patients who required specialist palliative care principally for cardiovascular disease, and whose death occurred between 1 January 2013 and 31 December 2022.

Methods: Five validated clinical instruments were used to collect point-of-care outcomes on each individual's function (Resource Utilisation Groups - Activities of Daily Living (RUG) & Australia-modified Karnofsky Performance Status (AKPS)), symptom distress (Symptoms Assessment Scale (SAS) & Palliative Care Problem Severity Score (PCPSS)) and other clinical characteristics (Palliative Care Phases). Multivariable logistic regression was applied to evaluate how patients' functional and symptom burden influenced their use of inpatient versus community-based palliative care services.

Results: Our analysis included 17,002 patients with cardiovascular disease, with 7,539 (44.3%) receiving community palliative care services and 9,463 (55.7%) accessing

inpatient palliative care services. Upon admission to palliative care services, patients often exhibit significant physical functional impairments and substantial symptom burdens, particularly related to fatigue and breathing difficulties. In comparison, patients accessing inpatient services tended to have greater functional impairment ($p < 0.001$) but commonly reported lower symptom burdens ($p < 0.001$). Our analysis indicated that greater functional impairment (ORs ranged from 2.53 to 6.02, $P < 0.001$ for RUG; ORs ranged from 1.72 to 5.02, $P < 0.008$ for AKPS), poorer overall health condition (OR ranged from 1.28 to 17.60, $P < 0.001$), and referrals by a community service (OR = 0.16, 95% confidence interval: 0.14-0.18, $P < 0.001$) were a negative predictor of inpatient services use. Surprisingly, higher levels of symptom distress and challenges in symptom management were associated with a decreased likelihood of utilizing inpatient services compared to community-based services.

Conclusion: Patients with cardiovascular disease frequently require support to manage decreased functional abilities, as well as symptoms like fatigue and breathing difficulties. With greater investment in community-based supportive services and a skilled palliative care workforce, more individuals with advanced cardiovascular disease could potentially receive palliative care in community settings.

Strengths and limitations of this study

- This study is the first large-scale, national investigation in Australia that specifically focuses on the clinical characteristics and care needs of patients with cardiovascular disease (CVD) receiving palliative care.
- It offers a comprehensive analysis of the factors influencing the utilization of various palliative care services by integrating diverse clinical characteristics, including functional impairment, symptom burden, referral patterns, and overall health condition.
- The multivariate models did not include other significant clinical factors (e.g., the need for management of edema and cognitive impairment) or social factors, which could influence the use of various types of palliative care services.
- The higher rate of proxy-reported assessments in the inpatient group, as compared to the community group, may have introduced discrepancies that affect the reliability of the data.

69 Introduction

70 Cardiovascular disease (CVD) is a leading cause of death in Australia and worldwide.¹
71 Individuals with severe stages of CVD often experience a diminished health-related quality
72 of life due to physical, psychological, and spiritual symptoms, as well as physical
73 disability.²⁻⁴

74 Palliative care is a patient- and family-centered approach aimed at optimizing patients'
75 quality of life by anticipating, preventing, and treating suffering in all its forms.⁵ It is
76 recommended for integration into the management of all chronic illnesses and can
77 complement curative treatments.^{2, 6-8} Robust evidence demonstrates that palliative care
78 significantly enhances patient satisfaction and overall quality of life.^{2, 9-11} Palliative care
79 should be accessible in all settings where patients require it, with a primary focus on both
80 community and hospital environments.^{5, 6, 12} Community-based and inpatient palliative
81 care differ in their structure and processes, yet both are essential for delivering
82 comprehensive care.¹³⁻¹⁵ Different types of palliative care are integral to ensuring patients
83 receive the necessary support tailored to their specific needs and circumstances.^{5, 15}

84 Despite the significant disease burden similar to that of cancer patients, palliative care is
85 currently underutilized in patients with advanced CVD.^{3, 16, 17} Addressing this disparity and
86 ensuring that CVD patients receive 'the right care, in the right place, at the right time'
87 presents a significant challenge in optimizing palliative care for this group.^{17, 18} Previous
88 research has predominantly focused on understanding the palliative care needs of this
89 patient group.¹⁹ However, there is a notable gap in exploring their patterns of palliative
90 care utilization, particularly how clinical characteristics and specific palliative care needs

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influence the use of different types of palliative care services. This area warrants further investigation to better tailor palliative care services to the unique requirements of this group. Therefore, our study used a nationwide sample of deceased cardiovascular patients to investigate: 1) patients' symptom and functional burden on their first admission to specialist palliative care services, and 2) how patients' symptom and functional burden and other clinical characteristics affected their utilization of community-based versus inpatient palliative care services. Our findings have the potential to guide policy development, optimize resource allocation, and enhance the training of healthcare professionals to improve the delivery of palliative care services tailored to the needs of patients with cardiovascular diseases.

Materials and METHODS

Data Source

Our study utilized anonymized patient outcome data from the Australian Palliative Care Outcomes Collaboration (PCOC), a national, government-funded initiative by the Australian Health Services Research Institute.²⁰ The PCOC aims to enhance the quality of palliative care through a systematic process involving routine assessments, measurement, reporting of patient outcomes, and benchmarking. The palliative care services registered with PCOC assess clinical outcomes of their patients using validated and standardized tools (refer to data collection tools below). Inpatient palliative care services conduct these assessments at admission, every 24 hours thereafter and at discharge to guide patient care. Community-based palliative services perform assessments on admission, during each subsequent patient contact and at discharge.

These assessments results are submitted to PCOC biannually and PCOC processes these data for validation and quality assurance. Based on this data, the PCOC national office generates biannual reports on clinical performance for each participating service. These services can then benchmark their performance against national averages and industry-agreed standards, fostering an environment of continuous improvement in palliative care.

Study Population and Settings

This study included individuals who satisfied the following criteria: (1) accessed specialist palliative care from Australian services registered with PCOC; (2) had CVD identified as the primary life-limiting condition necessitating palliative care; (3) their initial palliative care episode and death occurred between January 1, 2013, and December 31, 2022. The study specifically focused on the initial assessment conducted at the admission to the first episode of palliative care for each patient. An 'episode of care' is defined as a continuous period of care provided to a patient in a single care setting. The study examined patients from two categories of episodes: those in community-based settings and those in inpatient facilities. 'Inpatient episodes' document one of the overnight admitted options: designated palliative care beds or non-designated palliative care beds. 'Community episodes' document one of the community options: private residences or residential aged care facilities.

Variables and Data Collection Tools

The palliative care services registered with PCOC evaluate patients' clinical outcomes using five standardized and validated tools:

134 PCOC Symptom Assessment Scale (PCOC SAS): An 11-point scale ranging from 0
135 (absent) to 10 (worst possible), used to measure distress from common symptoms requiring
136 palliative care, such as sleep difficulties, appetite issues, nausea, bowel problems, breathing
137 difficulties, fatigue, and pain.²¹ This assessment is preferably done by patients; however,
138 proxy assessment is also acceptable when direct patient reporting is not feasible.

139 Palliative Care Problem Severity Score (PCPSS): Clinicians use this tool to assess the
140 global severity and complexity of patients' palliative care problems, including pain, other
141 symptoms, and psychological/spiritual and family/carer issues.²⁰ PCPSS is a 4-point scale
142 where 0 indicates absence and 3 signifies severe problems.

143 Resource Utilization Groups–Activities of Daily Living (RUG-ADL): This tool evaluates
144 patients' functional dependency levels in activities such as eating, toileting, bed mobility,
145 and transfers. Eating was assessed on a 3-point scale (1 for independent or supervision only,
146 3 for total dependence/tube fed), and the other activities on a 4-point scale (1/2 for
147 independent and monitor, 5 for assistance from two or more persons).²²

148 The Australia-modified Karnofsky Performance Status (AKPS) Scale evaluates a patient's
149 performance in terms of activity, work, and self-care. Clinicians assign a single score
150 ranging from 0 to 100, based on their observations of the patient's ability to perform typical
151 tasks related to these dimensions. A score of 100 represents normal physical abilities with
152 no signs of disease, while lower scores indicate diminished performance. A score of 0
153 signifies that the patient has died; however, this score is not used in the PCOC because no
154 further assessments are conducted after a patient's death.²⁰

PCOC Palliative Care Phases: The non-sequential PCOC palliative care phases which describe four distinct, clinically meaningful phases of palliative care (i.e., stable, unstable, deteriorating and terminal) were determined by clinicians based on comprehensive clinical assessments of the patient and their family. The palliative care phase identifies a clinically meaningful period in a patient's condition and served as the foundation for developing palliative care casemix classification. Detailed definitions of each phase can be found in the study by M. Masso et al.²⁰

Other variables included in this study involved demographic data such as sex, age group, country of birth, preferred language, referral source, year of admission, episode length, phase length, Socio-Economic Indexes for Areas (SEIFA), and place of death. SEIFA is a summary measure of social and economic conditions developed by the Australian Bureau of Statistics.²³

Statistical analysis

We described the characteristics of patients, their care episodes and clinical measures using frequency distributions and percentages. Differences between the two groups (inpatient vs. community) were assessed using Pearson's chi-square tests.

To investigate the impact of patients' functional and symptom burden, and other clinical characteristics on the utilization of inpatient versus community palliative care services, we employed multivariable logistic regression models. Significant factors associated with the utilization of different specialist services were identified through backward stepwise regression procedures. Due to substantial multicollinearity among elements of the RUG-ADL scale, only the 'total RUG-ADL' score was included in these stepwise analyses. The

criteria for inclusion and exclusion in the models were set at significance levels of 0.05 and 0.10, respectively. The model's fit was evaluated using the C-index, and P-values for trend were calculated. In our analyses, patients admitted to community-based services served as the reference group.

In our regression analyses, scores on the PCOC SAS, total RUG-ADL, and AKPS were reclassified as categorical variables as follows: PCOC SAS: Since less than 11% of patients had scores greater than 1 on four PCOC SAS symptom scores, the PCOC SAS was categorized into 0=absent (PCOC SAS=0), 1=mild (PCOC SAS=1-3), 2=moderate (PCOC SAS=4-7), and 3=moderate (PCOC SAS=8-10). AKPS: The categorization for AKPS was 1 = normal activity(AKPS=90-100), 2=symptomatic and ambulatory (AKPS = 70-80), 3=occasional assistance required (AKPS =60), 4 = increasingly limited mobility (AKPS = 30-50), 5 = completely bedfast (AKPS = 10 - 20). RUG-ADL: The categories for RUG-ADL were defined as RUG-ADL: 0 = independence or supervision only (total RUG-ADL = 4 - 5), 1 = limited physical assistance (RUG-ADL = 6 - 13), 2 = one assistant plus equipment (RUG-ADL = 14 - 17), 3 = two assistants for full care (RUG-ADL = 18)

We also fitted Kaplan-Meier curves and performed log-rank tests to compare survival time after the first episode of palliative care admission for the two groups.

Patient and Public Involvement Statement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

RESULTS

198 The characteristics of the study cohort and the community and inpatient episodes are shown
199 in supplemental table 1. The study cohort comprised 17,002 patients, of which 51.8% were
200 male, and 57.1% were aged 85 years or older. Additionally, 61.6% of patients were referred
201 from a hospital, followed by 33.0% referred from a community service. At the time of
202 accessing palliative care, nearly half (49.8%) of patients were in the deteriorating phases.

203 Within this cohort, 44.3% were from community-based palliative care services, and 55.7%
204 were from inpatient palliative care services. Compared to the inpatient group, patients in
205 the community group were more likely to be female ($P<0.001$) and older than 85 years
206 ($P<0.001$). A significantly higher proportion of patients in the inpatient group had an
207 episode length of less than one week ($P<0.001$) and were referred from a hospital. Patients
208 in the community group were predominantly assessed as being in the deteriorating (56.9%)
209 and stable (29.5%) phases, while the inpatient group was predominantly assessed as
210 deteriorating (44.1%), followed by terminal (22.6%) and unstable (20.3%) phases
211 ($P<0.001$). The survival curves indicate that the community group had a significantly
212 longer survival time compared to the inpatient group, suggesting that community episodes
213 of palliative care services were initiated much earlier than inpatient episodes. (Figure
214 1) Clinical outcome measures for both groups of patients are shown in supplemental table
215 2. Overall, patients in both groups exhibited high levels of functional and performance
216 impairment, with one-third being completely bedfast (AKPS score = 10-20) and requiring
217 two assistants for full care (Total RUG-ADL scores = 18). Significant differences in
218 function and performance impairment were observed between the two groups. The
219 proportions of patients in the inpatient group requiring two assistants for full care (43.30%
220 vs. 20.25%) or being completely bedfast (46.91% vs. 20.59%) were more than double those

221 of the community group ($P < 0.001$). Regarding the SAS assessments, severe levels of
222 distress were uncommon across all symptoms. Fatigue and breathing problems were the
223 top two sources of distress, causing moderate and severe levels of distress in more than
224 one-third of patients. In terms of assessments for palliative care problems (PCPSS),
225 approximately one-third of patients experienced moderate and severe levels of problems
226 related to other symptoms and family issues, compared to nearly 15% for psychological
227 problems and pain. A significant disparity in symptom burden was observed between the
228 two groups. Most often, the inpatient group had higher proportions of absent category,
229 fewer mild category, and equivalent moderate category across all symptom assessments (P
230 < 0.001 for each). The differences in the severe category between the two groups were not
231 evident due to the small proportion of this category for the both groups.

232 Supplemental table 3 presents the adjusted and unadjusted odds ratios (OR) for predictors
233 of inpatient service utilization, using community-based services as the reference group, as
234 determined by a multivariate logistic regression model with a c-statistic of 0.89. Only the
235 adjusted ORs are reported here. Among sociodemographic factors, higher SEIFA scores
236 (adjusted OR ranged from 1.34 to 2.18; $p < 0.001$) are positively associated with utilizing
237 inpatient services. Conversely, female patients (adjusted OR: 0.82; 95% CI: 0.73-0.91; $p <$
238 0.001), older age (adjusted ORs ranged from 0.52 to 0.81; $p < 0.001$), being born in a
239 country other than Australia (adjusted ORs ranged from 0.58 to 0.88; $p < 0.001$), and years
240 closer to 2022 (adjusted ORs ranged from 0.42 to 0.85; $p < 0.001$) were negatively
241 associated with accessing community-based services. As indicated by the p-values for
242 trend, dose-response associations were observed for the factors of ages ($p < 0.001$), SEIFA
243 ($p < 0.001$) and years of admission ($p < 0.001$).

In terms of clinical characteristics, the most significant factor predicting use of inpatient services was patients being assessed in the unstable phase (adjusted OR: 17.60; 95% CI: 14.15-21.90; $p < 0.001$). Higher scores on RUG-ADL and lower scores on AKPS were linked to increased likelihood of entering inpatient services. Regarding symptom burden, moderate (adjusted OR: 1.20; 95% CI: 1.02-1.40; $p = 0.024$) and severe (adjusted OR: 1.74; 95% CI: 1.32-2.29; $p < 0.001$) breathing problems assessed by PCOC SAS, as well as severe bowel problems (OR: 1.72; 95% CI: 1.03-2.86; $p = 0.038$), positively predicted use of inpatient services compared to absence of these symptoms. Conversely, from mild to moderate levels, symptoms such as insomnia, fatigue, and family issues assessed by PCPSS were consistently associated with lower odds of using inpatient services. Additionally, dose-response associations were identified for all symptom and function-related factors, with a p-value for trend of less than 0.001 for each.

Ethics approval and consent to participate

The PCOC program has been approved by Human Research Ethics Committee (HREC) of the University of Wollongong (HE06/045) and this study was granted waiver of consent by The University of Western Australia HREC (RA/4/1/8365).

DISCUSSION

Our population-based national study examined the symptom and functional burden of CVD patients on their first admission to specialist palliative care services, as well as how these burdens and other clinical characteristics influenced their use of different types of specialist services in Australia. Compared to the community group, the inpatient group exhibited

266 significantly greater dependency and poorer performance, yet reported higher proportions
267 of absent symptom burden and fewer instances of mild symptom burden. An unstable
268 palliative phase, along with greater dependency and poorer performance, predicted the use
269 of inpatient services. Surprisingly, increased symptom burden was often associated with a
270 lower likelihood of utilizing inpatient services compared to community services.

271 Previous studies have extensively documented that fatigue, breathing problems, and
272 functional disabilities are common among palliative care patients with CVD.^{4, 19, 24-26} In
273 our study, patients reported higher levels of distress from fatigue and breathing problems
274 compared to other symptoms. These two symptoms, which are often prevalent and
275 concurrent, pose significant management challenges and are closely linked to impaired
276 quality of life in CVD patients. For instance, a 2019 multicenter study in the U.S. involving
277 1,801 palliative care patients with CVD found that the most common symptoms were
278 tiredness (50.3%), anorexia (35.7%), and dyspnea (27.9%).²⁶ Additionally, 38.9% of these
279 patients were bedridden and fully dependent,²⁶ a finding consistent with our study's report
280 of 35.17% of patients being completely bedfast. Beyond symptom management, our study
281 also underscores the importance of addressing family needs and issues, a concern that has
282 been increasingly emphasized in the international palliative care literature.

283 Our study compared the symptom burden and function impairment between patients
284 referred to community and inpatient services. We discovered that inpatient groups
285 generally reported higher functional disability and lower symptom burden than their
286 community counterparts. The findings regarding function were plausible, given that the
287 inpatient group had a much shorter survival time and a significantly higher proportion of
288 patients in the unstable and terminal stages compared to the community group. However,

the findings that inpatient group reported lower symptom burdens were unexpected and inconsistent with our previous studies focusing on the PCOC cohorts of lung cancer,²⁷ dementia²⁸ and stroke.²⁹ One possible explanation relates to referral sources: 83.1% of inpatient group patients were referred from hospitals, while 56.5% of community group patients were referred from community services. It is likely that hospital-referred patients had better-managed symptoms before being referred to palliative care services. Nevertheless, given that palliative care focuses on symptom management, these findings necessitate further exploration of the determinants for patients accessing different types of palliative care services.

Our analyses contributed new insights by identifying the factors that predict the use of inpatient services compared to community-based services. We found that patients from areas with higher social and economic conditions were more likely to use inpatient services. This is likely attributable to the fact that most Australian palliative care workforce are employed in hospital settings in major cities.³⁰ Additionally, our regression model indicated that community services were more widely used in most years between 2014 and 2022 compared to 2013, although the pattern did not persist after 2020, possibly due to the impact of COVID-19. This finding suggests that the efforts of advocacy for increased use of community services has been effective.^{31, 32} Unsurprisingly, referrals from hospitals strongly predict the use of hospital palliative care services, given that many hospitals have a palliative care unit or designated palliative care beds. We also identified that being female and older age were associated with a higher likelihood of using community palliative care services. Further studies are needed to explore the underlying reasons for these associations.

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311 Inpatient services, equipped to provide around-the-clock specialized care, can promptly
312 address patients' complex and urgent symptom management needs.¹⁵ However, our
313 analysis showed that a higher symptom burden was not consistently linked to the use of
314 inpatient services compared to community services. Instead, individuals with a higher
315 symptom burden were more likely to access community services in most situations. These
316 findings indicate that delivery of palliative care service for patients with CVD could benefit
317 from promoting a needs-based care model. However, consensus on need-based palliative
318 care referral criteria in patients with CVD remains lacking.^{18, 33} It should also be noted that
319 the lower symptom burden observed in the inpatient group was likely due to decreased
320 activity levels, given the substantially higher proportion of bedfast patients in this group
321 compared to the community group. Elevated clinician-rated scores for family issues were
322 also associated with lower likelihood of using inpatient services in our study. This could
323 be because community healthcare providers, who are more familiar with the family than
324 hospital providers, tend to rate family burden and concerns higher.

325 There was a higher utilization of inpatient services associated with higher levels of
326 dependency and lower functional performance status. Relocating these individuals to an
327 inpatient setting and abruptly altering their living environments may cause increased
328 distress, confusion, and a heightened risk of falls and injuries. For most people in our study
329 without severe or complex symptoms, a more patient-centered management model, based
330 in their usual residence and involving highly trained staff to support families and caregivers,
331 would be optimal. Therefore, a community-based model is suitable for patients with major
332 functional disabilities but not experiencing severe symptoms.

Moreover, community-based palliative care services have gained popularity not only because they are more cost-effective compared to inpatient services,³⁴ but also because they facilitate continuity of care by maintaining connections with the patients' regular care providers and enabling patients to stay and die at their preferred place.³⁴ However, it is important to note that home-care arrangements demand significant physical, emotional, and financial commitment from families and caregivers. Many families and caregivers may become fatigued and overwhelmed, or feel unsafe as the patient's condition worsens or if unexpected health changes occur. A common reaction in these situations is to seek institutional care. This aligns with our findings, which indicate increased access to inpatient services for individuals in non-stable (especially unstable) palliative care phases compared to stable phase. Enhanced support for carers and families of people with CVD tends to facilitate longer periods of home care.²⁵

Strengths and limitations

To our knowledge, this is the first large-scale, national study that comprehensively examines the clinical characteristics, care needs, and their associations with the use of different types of palliative care services specifically for people with cardiovascular disease (CVD) in Australia. While the analyses were enhanced by the use of standardized and validated instruments at the point of care, several limitations should be acknowledged. First, some bias may have been introduced by the criteria used for disease classifications in these data. Given that the PCOC only captures the primary diagnosis that necessitates the episode of palliative care, patients included in this study may also had other common comorbidities except for CVD, such as diabetes and dementia. Second, our multivariate models focused on palliative care needs related to symptom and functional burden, but did

not include other clinical factors (e.g., need for management of edema and cognitive impairment, etc.) or social factors (e.g., availability of informal carers). These significant and unique characteristics of advanced CVD are important considerations in decisions about the types of services to utilize. Third, the inpatient groups likely had a higher rate of proxy-reported SAS assessments compared to the community groups, given that more patients in the inpatient group were at a later stage of life. The potential discrepancies between patient-reported and proxy-reported outcomes may have introduced bias into our data. Given these limitations, the symptom outcomes reported in this study should be interpreted with caution.

Conclusion

On admission to specialist palliative care services, patients with CVD exhibit high degrees of physical impairment and distress associated with fatigue and breathing problems. Comparatively, patients entering inpatient services required higher levels of physical assistance but often reported lower levels of symptom burden. Our most notable finding is that elevated symptom distress and difficulties in managing these symptoms unexpectedly predicted a decrease in the utilization of inpatient services compared to community services. Based on these findings, we concluded that there is a significant need to develop a CVD-specific palliative care pathway or referral guidelines to promote needs-based palliative care delivery models. Such a model could enable a larger number of people with advanced CVD to receive care and spend the end of life in their usual accommodations. Promoting these models would require greater investment in supportive services, such as skilled palliative care staff and support for carers, in the community.

Contributors:

XQ conceived the concept, designed the study. ML drafted the manuscript, conducted data analysis and interpretation together with SQ and HL. JD provided served as the guarantor, led the data application from the Palliative Care Outcomes Collaboration. XQ, ML, SQ, HL, JJ, MT, HT, and JD critically reviewed and provided feedback on the manuscript. All authors approved the final version for submission.

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conflicts of interest

None

Reference

- (1) Naghavi, M.; Ong, K. L.; Aali, A.; Ababneh, H. S.; Abate, Y. H.; Abbafati, C.; Abbasgholizadeh, R.; Abbasian, M.; Abbasi-Kangevari, M.; Abbastabar, H. Global burden of 288 causes of death and life expectancy decomposition in 204 countries and territories and 811 subnational locations, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *The Lancet* **2024**, *403* (10440), 2100-2132.
- (2) Hill, L.; Prager Geller, T.; Baruah, R.; Beattie, J. M.; Boyne, J.; de Stoutz, N.; Di Stolfo, G.; Lambrinou, E.; Skibelund, A. K.; Uchmanowicz, I. Integration of a palliative approach into heart failure care: a European Society of Cardiology Heart Failure Association position paper. *European journal of heart failure* **2020**, *22* (12), 2327-2339.

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(3) Ding, J.; Johnson, C. E.; Lee, Y. C.; Gazey, A.; Cook, A. Characteristics of people with dementia vs other conditions on admission to inpatient palliative care. *Journal of the American Geriatrics Society* **2020**, *68* (8), 1825-1833.

(4) Chan, H. Y.; Doris, S.; Leung, D. Y.; Chan, A. W.; Hui, E. Quality of life and palliative care needs of elderly patients with advanced heart failure. *Journal of geriatric cardiology: JGC* **2016**, *13* (5), 420.

(5) Radbruch, L.; De Lima, L.; Knaut, F.; Wenk, R.; Ali, Z.; Bhatnagar, S.; Blanchard, C.; Bruera, E.; Buitrago, R.; Burla, C. Redefining palliative care—a new consensus-based definition. *Journal of pain and symptom management* **2020**, *60* (4), 754-764.

(6) Kaasa, S.; Loge, J. H.; Aapro, M.; Albrecht, T.; Anderson, R.; Bruera, E.; Brunelli, C.; Caraceni, A.; Cervantes, A.; Currow, D. C. Integration of oncology and palliative care: a Lancet Oncology Commission. *The lancet oncology* **2018**, *19* (11), e588-e653.

(7) Lewin, W. H.; Schaefer, K. G. Integrating palliative care into routine care of patients with heart failure: models for clinical collaboration. *Heart failure reviews* **2017**, *22*, 517-524.

(8) Puckett, C.; Goodlin, S. J. A modern integration of palliative care into the management of heart failure. *Canadian Journal of Cardiology* **2020**, *36* (7), 1050-1060.

(9) Quinn, K. L.; Stukel, T.; Stall, N. M.; Huang, A.; Isenberg, S.; Tanuseputro, P.; Goldman, R.; Cram, P.; Kavalieratos, D.; Detsky, A. S. Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: population based matched cohort study. *Bmj* **2020**, *370*.

(10) Bakitas, M. A.; Dionne-Odom, J. N.; Ejem, D. B.; Wells, R.; Azuero, A.; Stockdill, M. L.; Keebler, K.; Sockwell, E.; Tims, S.; Engler, S. Effect of an early palliative care telehealth intervention vs usual care on patients with heart failure: the ENABLE CHF-PC randomized clinical trial. *JAMA internal medicine* **2020**, *180* (9), 1203-1213.

(11) Ting, J.; Songer, K.; Bailey, V.; Rotman, C.; Lipsitz, S.; Rosenberg, A. R.; Delgado-Corcoran, C.; Moynihan, K. M. Impact of Subspecialty Pediatric Palliative Care on Children with Heart Disease; A Systematic Review and Meta-analysis. *Pediatric Cardiology* **2024**, 1-15.

(12) Axelsson, B. The challenge: equal availability to palliative care according to individual need regardless of age, diagnosis, geographical location, and care level. *International Journal of Environmental Research and Public Health* **2022**, *19* (7), 4229.

- (13) Kamal, A. H.; Currow, D. C.; Ritchie, C. S.; Bull, J.; Abernethy, A. P. Community-based palliative care: the natural evolution for palliative care delivery in the US. *Journal of pain and symptom management* **2013**, *46* (2), 254-264.
- (14) Brereton, L.; Clark, J.; Ingleton, C.; Gardiner, C.; Preston, L.; Ryan, T.; Goyder, E. What do we know about different models of providing palliative care? Findings from a systematic review of reviews. *Palliative medicine* **2017**, *31* (9), 781-797.
- (15) Wiencek, C.; Coyne, P. Palliative care delivery models. In *Seminars in oncology nursing*, 2014; Elsevier: Vol. 30, pp 227-233.
- (16) Liu, A. Y.; O'Riordan, D. L.; Marks, A. K.; Bischoff, K. E.; Pantilat, S. Z. A comparison of hospitalized patients with heart failure and cancer referred to palliative care. *JAMA network open* **2020**, *3* (2), e200020-e200020.
- (17) Quinn, K. L.; Wegier, P.; Stukel, T. A.; Huang, A.; Bell, C. M.; Tanuseputro, P. Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA network open* **2021**, *4* (3), e210677-e210677.
- (18) Chang, Y. K.; Kaplan, H.; Geng, Y.; Mo, L.; Philip, J.; Collins, A.; Allen, L. A.; McClung, J. A.; Denvir, M. A.; Hui, D. Referral criteria to palliative care for patients with heart failure: a systematic review. *Circulation: Heart Failure* **2020**, *13* (9), e006881.
- (19) Quattrone, F.; Aimo, A.; Zuccarino, S.; Morelli, M. S.; Morfino, P.; Gioia, A.; Passino, C.; Ferrè, F.; Nuti, S.; Emdin, M. Unmet needs in end-of-life care for heart failure patients. *International Journal of Cardiology* **2024**, *399*, 131750.
- (20) University of Wollongong. *Palliative Care Outcomes Collaboration*. 2024. <https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/> (accessed 2024 June 30).
- (21) Daveson, B. A.; Allingham, S. F.; Clapham, S.; Johnson, C. E.; Currow, D. C.; Yates, P.; Eagar, K. The PCOC Symptom Assessment Scale (SAS): A valid measure for daily use at point of care and in palliative care programs. *PLoS One* **2021**, *16* (3), e0247250.
- (22) Fries, B. E.; Schneider, D. P.; Foley, W. J.; Gavazzi, M.; Burke, R.; Cornelius, E. Refining a case-mix measure for nursing homes: Resource Utilization Groups (RUG-III). *Medical care* **1994**, *32* (7), 668-685.
- (23) Australian Bureau of Statistics. *Socio-Economic Indexes for Areas*. 2023. <https://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa> (accessed 2024 June 30).

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(24) Gonzalez-Jaramillo, V.; Maessen, M.; Luethi, N.; Guyer, J.; Hunziker, L.; Eychmüller, S.; Zambrano, S. C. Unmet needs in patients with heart failure: the importance of palliative care in a heart failure clinic. *Frontiers in cardiovascular medicine* **2022**, *9*, 866794.

(25) Ganz, F. D.; Roeh, K.; Eid, M.; Hasin, T.; Harush, C.; Gotsman, I. The need for palliative and support care services for heart failure patients in the community. *European Journal of Cardiovascular Nursing* **2021**, *20* (2), 138-146.

(26) Warraich, H. J.; Wolf, S. P.; Mentz, R. J.; Rogers, J. G.; Samsa, G.; Kamal, A. H. Characteristics and trends among patients with cardiovascular disease referred to palliative care. *JAMA Network Open* **2019**, *2* (5), e192375-e192375.

(27) Ding, J.; Johnson, C. E.; Qin, X.; Ho, S. C.; Cook, A. Palliative care needs and utilisation of different specialist services in the last days of life for people with lung cancer. *European Journal of Cancer Care* **2021**, *30* (1), e13331.

(28) Ding, J.; Cook, A.; Qin, X.; Ho, S. C.; Johnson, C. E. Palliative care needs and utilization of specialist services for people imminently dying with dementia: A national population-based study. *International Journal of Nursing Studies* **2020**, *109*, 103655.

(29) Liu, H.; Cook, A.; Ding, J.; Lu, H.; Jiao, J.; Bai, W.; Johnson, C. E. Palliative care needs and specialist services post stroke: national population-based study. *BMJ Supportive & Palliative Care* **2024**, *14* (e1), e1422-e1431.

(30) Australian Institute of Health and Welfare. *Palliative care services in Australia*. 2024. <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce> (accessed 2024 June 30).

(31) *National Palliative Care Strategy 2018*, 2018. <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>.

(32) Shadd, J. D.; Burge, F.; Stajduhar, K. I.; Cohen, S. R.; Kelley, M. L.; Pesut, B. Defining and measuring a palliative approach in primary care. *Canadian Family Physician* **2013**, *59* (11), 1149-1150.

(33) Chang, Y. K.; Allen, L. A.; McClung, J. A.; Denvir, M. A.; Philip, J.; Mori, M.; Perez-Cruz, P.; Cheng, S.-Y.; Collins, A.; Hui, D. Criteria for referral of patients with advanced heart failure for specialized palliative care. *Journal of the American College of Cardiology* **2022**, *80* (4), 332-344.

(34) Spilsbury, K.; Rosenwax, L. Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life. *BMC palliative care* **2017**, *16*, 1-12.

Legend

Figure 1. Survival curves for patients with CVD referred to inpatient versus community palliative care services. Comparison between the two groups was performed using log-rank tests.

Supplemental Table 1. Sociodemographic and clinical characteristics for people with CVD by episode settings

Supplemental Table 2. Clinical measure outcomes for patients with CVD by episode settings

Supplemental Table 3. Regression analyses for factors associated with inpatient versus community palliative care

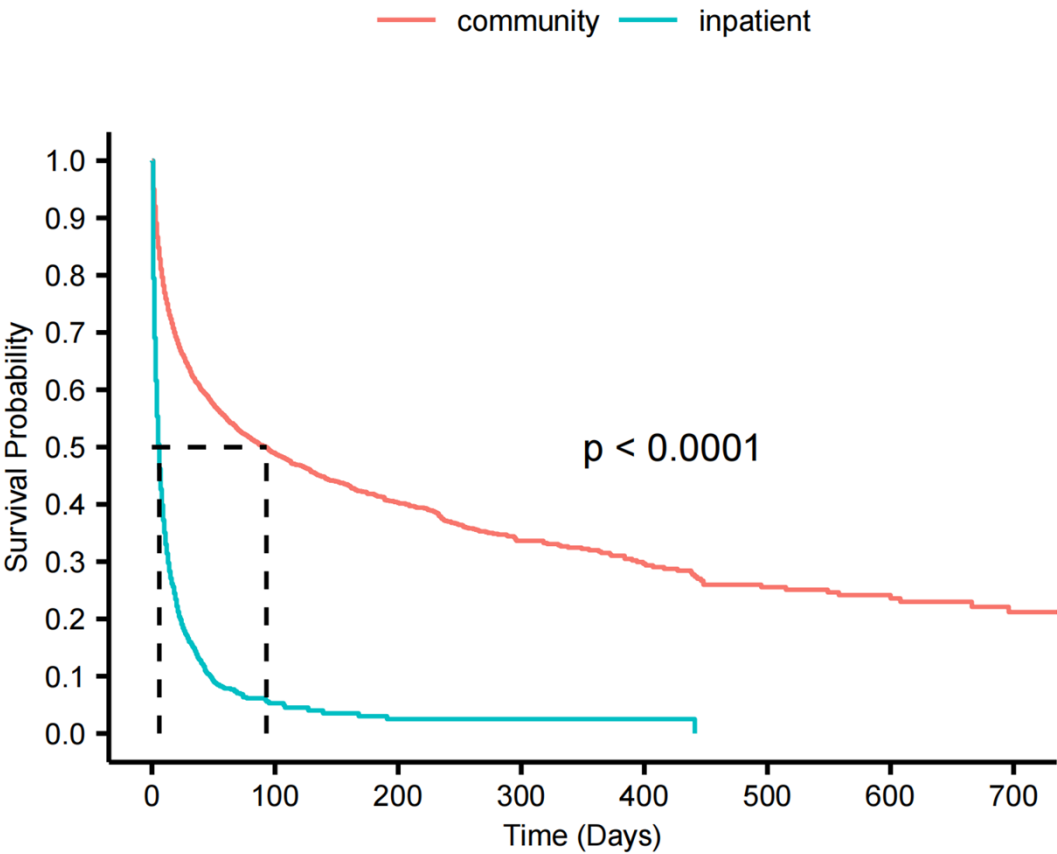


Table 1 Sociodemographic and clinical characteristics for people with CVD by episode settings

Characteristics of Patients		All N (%)	Community N (%)	Inpatient N (%)	P values
Sociodemographic characteristics					
Total number		17,002(100)	7,539(44.3)	9,463(55.7)	
	Male	8,813(51.8)	3,734(49.5)	5,079(53.7)	
Sex	Female	8,179(48.1)	3,798(50.4)	4,381(46.3)	<0.001
	Missing	10(0.1)	7(0.1)	3(0.0)	
	≤74	2581(15.2)	904(12)	1677(17.7)	
Age group	75-84	4,714(27.7)	1,899(25.2)	2,815(29.7)	<0.001
	85-94	7,865(46.3)	3,674(48.7)	4191(44.3)	
	≥95	1,838(10.8)	1,058(14.0)	780(8.2)	
	Missing	4(0.0)	4(0.1)	0(0.0)	
	1-2	2,232(13.1)	959(12.7)	1,273(13.5)	
SEIFA	3-4	2470(14.5)	991(13.1)	1479(15.6)	<0.001
	5-6	3360(19.8)	1378(18.3)	1982(20.9)	

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Preferred language	7-8	3487(20.5)	1351(17.9)	2136(22.6)	<0.001
	9-10	5350(31.5)	2791(37.0)	2559(27.0)	
	Missing	103(0.6)	69(0.9)	34(0.4)	
	English	14680(86.3)	6560(87.0)	8120(85.8)	
	Non-English	2103(12.4)	848(11.2)	1255(13.3)	
	Missing	219(1.3)	131(1.7)	88(0.9)	
	Australia	10154(59.7)	4364(57.9)	5790(61.2)	
	England	1093(6.4)	529(7.0)	564(6.0)	
	Italy	1160(6.8)	513(6.8)	647(6.8)	
	Greece	531(3.1)	241(3.2)	290(3.1)	
Country of birth	Else	3723(21.9)	1632(21.6)	2091(22.1)	0.013
	Missing	341(2.0)	260(3.4)	81(0.9)	
Characteristics of episode	2013	1092(6.4)	393(5.2)	699(7.4)	
	2014	1312(7.7)	523(6.9)	789(8.3)	
	2015	1356(8.0)	626(8.3)	730(7.7)	

Year of episode start	2016	1489(8.8)	655(8.7)	834(8.8)	<0.001
	2017	1598(9.4)	670(8.9)	928(9.8)	
	2018	1718(10.1)	799(10.6)	919(9.7)	
	2019	2035(12.0)	981(13.0)	1054(11.1)	
	2020	2589(15.2)	1278(17.0)	1311(13.9)	
	2021	2663(15.7)	1132(15.0)	1531(16.2)	
	2022	1150(6.8)	482(6.4)	668(7.1)	
	≤1 week	9558(56.2)	2442(32.4)	7116(75.2)	
	1-2week	2222(13.1)	987(13.1)	1235(13.1)	
	2-3 week	1170(6.9)	685(9.1)	485(5.1)	
Episode length	3-4 week	720(4.2)	486(6.4)	234(2.5)	<0.001
	>4 week	3332(19.6)	2939(39.0)	393(4.2)	
	Stable	3452(20.3)	2225(29.5)	1227(13.0)	
	Unstable	2274(13.4)	353(4.7)	1921(20.3)	
	Deteriorating	8462(49.8)	4290(56.9)	4172(44.1)	
Phase type	Terminal	2814(16.6)	671(8.9)	2143(22.6)	<0.001

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Referral source	Hospital	10469(61.6)	2603(34.5)	7866(83.1)	<0.001
	Community service	5619(33.0)	4263(56.5)	1356(14.3)	
	Others	774(4.6)	581(7.7)	193(2.0)	
	Missing	140(0.8)	92(1.2)	48(0.5)	

Abbreviations: SEIFA: Socio-Economic Indexes for Areas (scores 1 –10).
Comparisons between the two groups were conducted using Pearson’s chi-square tests. Missing data entries were not accounted for in the analyses.

Table 2 Clinical measure outcomes for patients with CVD by episode settings

		All		Community		Inpatients	P value
		N	%	N	%	%	
SAS Insomnia	Absent	10055	66.95%	4002	58.02%	74.54%	<0.001
	Mild	3088	20.56%	1920	27.83%	14.38%	
	Moderate	1544	10.28%	819	11.87%	8.93%	
	Severe	331	2.20%	157	2.28%	2.14%	
SAS Appetite problems	Absent	9429	61.84%	3795	53.24%	69.39%	<0.001
	Mild	3760	24.66%	2316	32.49%	17.79%	
	Moderate	1699	11.14%	848	11.90%	10.48%	
	Severe	359	2.35%	169	2.37%	2.34%	
SAS Nausea	Absent	12792	83.79%	5745	80.54%	86.65%	<0.001
	Mild	1785	11.69%	1077	15.10%	8.71%	
	Moderate	583	3.82%	272	3.81%	3.82%	
	Severe	106	0.69%	39	0.55%	0.82%	

SAS Bowels problems	Absent	10458	68.85%	4369	61.70%	6089	75.09%	<0.001
	Mild	3345	22.02%	2063	29.13%	1282	15.81%	
	Moderate	1183	7.79%	582	8.22%	601	7.41%	
	Severe	204	1.34%	67	0.95%	137	1.69%	
SAS Breathing problems	Absent	5683	37.14%	2259	31.55%	3424	42.05%	<0.001
	Mild	4966	32.45%	2794	39.02%	2172	26.67%	
	Moderate	3816	24.94%	1799	25.13%	2017	24.77%	
	Severe	838	5.48%	308	4.30%	530	6.51%	
SAS Fatigue	Absent	5884	38.53%	1983	27.75%	3901	48.02%	<0.001
	Mild	4416	28.92%	2658	37.19%	1758	21.64%	
	Moderate	3892	25.49%	2022	28.29%	1870	23.02%	
	Severe	1079	7.07%	484	6.77%	595	7.32%	
SAS Pain	Absent	7380	48.14%	3046	42.31%	4334	53.31%	<0.001
	Mild	5313	34.66%	3003	41.71%	2310	28.41%	
	Moderate	2213	14.44%	997	13.85%	1216	14.96%	
	Severe	424	2.77%	154	2.14%	270	3.32%	

PCPSS Pain	Absent	7850	47.17%	3169	42.65%	4681	50.82%	<0.001
	Mild	6337	38.08%	3213	43.24%	3124	33.92%	
	Moderate	2049	12.31%	901	12.13%	1148	12.46%	
	Severe	405	2.43%	147	1.98%	258	2.80%	
PCPSS Other symptoms	Absent	3633	22.63%	1228	17.64%	2405	26.45%	<0.001
	Mild	7477	46.58%	3602	51.75%	3875	42.62%	
	Moderate	4165	25.95%	1886	27.10%	2279	25.07%	
	Severe	776	4.83%	244	3.51%	532	5.85%	
PCPSS Psychological	Absent	6823	40.89%	2604	35.44%	4219	45.19%	<0.001
	Mild	7476	44.81%	3684	50.14%	3792	40.61%	
	Moderate	2065	12.38%	944	12.85%	1121	12.01%	
	Severe	321	1.92%	116	1.58%	205	2.20%	
PCPSS Family	Absent	4259	26.80%	1424	20.02%	2835	32.30%	<0.001
	Mild	7577	47.69%	3726	52.38%	3851	43.88%	
	Moderate	3396	21.37%	1725	24.25%	1671	19.04%	
	Severe	657	4.13%	238	3.35%	419	4.77%	

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Total RUG-ADL	Independent	2448	14.83%	1823	25.39%	625	6.70%	<0.001
	Limited physical assistance	4838	29.31%	2511	34.97%	2327	24.95%	
	Requires one assistant plus equipment	3728	22.59%	1393	19.40%	2335	25.04%	
	Requires two assistants for full care	5492	33.27%	1454	20.25%	4038	43.30%	
	Independent or supervision only	2757	16.61%	2060	28.43%	697	7.45%	
Transfer	Limited physical assistance	3217	19.38%	1672	23.07%	1545	16.52%	<0.001
	Other than two persons physical assist	2602	15.68%	1243	17.15%	1359	14.53%	
	Two-person (or more) physical assist	8022	48.33%	2272	31.35%	5750	61.49%	
	Independent or supervision only	4050	24.37%	2719	37.42%	1331	14.23%	
Mobility	Limited physical assistance	2899	17.44%	1399	19.25%	1500	16.04%	<0.001
	Other than two persons physical assist	2261	13.60%	1038	14.28%	1223	13.08%	

Toileting	Two-person (or more) physical assist	7410	44.58%	2111	29.05%	5299	56.66%	<0.001
	Independent or supervision only	2776	16.71%	2078	28.61%	698	7.46%	
	Limited physical assistance	3260	19.62%	1659	22.84%	1601	17.12%	
	Other than two persons physical assist	2796	16.83%	1295	17.83%	1501	16.05%	
	Two-person (or more) physical assist	7782	46.84%	2231	30.72%	5551	59.36%	
Eating	Independent or supervision only	6190	37.45%	3580	49.70%	2610	27.99%	<0.001
	Limited assistance	3946	23.87%	1801	25.00%	2145	23.00%	
	Extensive assistance/total dependence/tube fed	6393	38.68%	1822	25.30%	4571	49.01%	
	Normal activity(AKPS=90-100)	29	0.17%	18	0.24%	11	0.12%	
AKPS	Symptomatic and ambulatory(AKPS=70-80)	425	2.54%	343	4.59%	82	0.88%	<0.001
	Occasional assistance	1343	8.02%	945	12.65%	398	4.29%	

required(AKPS=60)						
Increasingly limited mobility(AKPS=30-50)	9058	54.10%	4628	61.93%	4430	47.79%
Completely bedfast (AKPS=10-20)	5888	35.17%	1539	20.59%	4349	46.91%

Abbreviations: SAS: Symptom Assessment Scale. PCPSS: Palliative Care Problem Severity Score, RUG-ADL: Resource Utilisation Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, Comparisons between two groups were conducted using Pearson’s chi-square tests. Missing data entries were not accounted for in the analyses.

Table 3 Regression analyses for factors associated with inpatient versus community palliative care

	Inpatient vs community Unadjusted OR (95%CI, p-value)†	Inpatient vs community Adjusted OR (95%CI, p-value)†	P value for trend
Sex (ref. male)	0.85(0.80-0.90; <0.001)	0.82(0.77-0.91; <0.001)	
Age group (ref. ≤ 74 years)			
75-84	0.80(0.72-0.88; <0.001)	0.81(0.73-0.96; 0.015)	
85-94	0.62(0.56-0.67; <0.001)	0.69(0.59-0.82; <0.001)	<0.001*
≥95	0.40(0.35-0.45; <0.001)	0.52(0.41-0.65; <0.001)	
Country of birth (ref. Australia)			
England	0.80(0.71-0.91; 0.001)	0.78(0.63-0.97; 0.025)	
Italy	0.95(0.84-1.07; 0.417)	0.87(0.69-1.11; 0.265)	
Greece	0.91(0.76-1.08; 0.275)	0.58(0.42-0.80; 0.001)	
Else	0.97(0.90-1.04; 0.366)	0.88(0.66-1.17; 0.067)	
Preferred language (ref. English)	1.20(1.09-1.31; <0.001)	0.81(0.66-0.99; 0.040)	
SEIFA (ref.1-2)			
3-4	1.45(1.31-1.60; < 0.001)	1.34 (1.09-1.65; 0.005)	
5-6	1.63(1.48-1.79; < 0.001)	1.80(1.49-2.18; < 0.001)	<0.001*

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Year of episode start (ref. 2013)			
7-8	1.57(1.44-1.71; <0.001)	2.18(1.89-2.53; <0.001)	
9-10	1.72(1.58-1.88; <0.001)	1.61(1.37-1.93; <0.001)	
2014	1.28(1.08-1.52; 0.004)	0.85(0.61-1.11; 0.230)	
2015	1.09(0.93-1.28; 0.302)	0.52(0.44-0.68; <0.001)	
2016	0.84(0.72-0.99; 0.033)	0.61(0.49-0.79; <0.001)	
2017	0.92(0.79-1.07; 0.286)	0.70(0.53-0.91; 0.008)	
2018	1.00(0.86-1.17; 0.994)	0.43(0.33-0.56; <0.001)	<0.001*
2019	0.83(0.71-0.97; 0.015)	0.42(0.33-0.55; <0.001)	
2020	0.78(0.67-0.90; 0.001)	0.54(0.42-0.70; <0.001)	
2021	0.74(0.64-0.85; <0.001)	0.72(0.56-0.92; 0.009)	
2022	0.98(0.85-1.12; 0.733)	0.81(0.60-1.09; 0.161)	
Referral source (ref. hospital)			
Community service	0.11(0.10-0.11; <0.001)	0.16(0.14-0.18; <0.001)	
Others	0.11(0.09-0.13; <0.001)	0.15(0.12-0.19; <0.001)	
Phase type (ref. stable)			

Unstable	0.17(0.15-0.19; <0.001)	17.60 (14.55-21.90; <0.001)	
Deteriorating	1.70(1.48-1.97; <0.001)	1.28 (1.00-1.48; 0.001)	
Terminal	0.31(0.28-0.34; <0.001)	1.49(1.15-1.86; <0.001)	
RUG Total (ref. independent)			
Limited physical assistance	0.12(0.11-0.14; <0.001)	2.53(2.03-3.05; <0.001)	
Requires one assistant plus equipment	0.33(0.31-0.36; <0.001)	4.43(3.53-5.38; <0.001)	<0.001*
Requires two assistants for full care	0.60(0.55-0.66; <0.001)	6.02(4.60-7.83; <0.001)	
AKPS (ref. AKPS=70-100)			
AKPS=60	1.64(1.27-2.11; <0.001)	1.72(1.15-2.56; 0.008)	
AKPS=50	2.08(1.63-2.64; <0.001)	2.23(1.50-3.30; <0.001)	<0.001*
AKPS=30-40	5.12(4.05-6.47; <0.001)	4.18(2.80-6.26; <0.001)	
AKPS=10-20	10.97(8.67-13.88; <0.001)	5.02(3.26-7.74; <0.001)	
SAS score for insomnia (ref.absent)			
Mild	1.37(1.10-1.70; 0.005)	0.64(0.45-0.74; <0.001)	
Moderate	0.55(0.44-0.69; <0.001)	0.58(0.48-0.70; <0.001)	<0.001*
Severe	0.80(0.63-1.01; 0.064)	0.43(0.29-0.63; <0.001)	

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SAS score for appetite (ref.absent)				
Mild	1.32(1.07-1.63; 0.010)	0.79(0.48-0.90; 0.001)		
Moderate	0.56(0.45-0.69; <0.001)	0.89(0.71-1.08; 0.240)		<0.001*
Severe	0.89(0.71-1.12; 0.329)	0.77(0.58-1.14; 0.194)		
SAS score for nausea (ref.absent)				
Mild	0.54(0.48-0.59 ; <0.001)	0.94(0.71-1.12; 0.490)		
Moderate	0.93(0.79-1.10 ; 0.408)	1.28(0.77-1.69; 0.076)		<0.001*
Severe	1.40(0.94-2.08 ; 0.096)	1.82(0.93-2.55; 0.082)		
SAS score for bowels (ref.absent)				
Mild	0.68(0.51-0.92; 0.011)	0.61 (0.4-0.71; <0.001)		
Moderate	0.30(0.23-0.41; <0.001)	0.80 (0.55-0.99; 0.036)		<0.001*
Severe	0.51(0.37-0.69; <0.001)	1.72 (1.33-1.86; 0.038)		
SAS score for breathing(ref. absent)				
Mild	0.88(0.76-1.02; 0.098)	0.93 (0.81-1.07; 0.322)		<0.001*

Moderate	0.45(0.39-0.53; <0.001)	1.20 (1.02-1.40; 0.024)	
Severe	0.65(0.56-0.76; <0.001)	1.74 (1.32-2.29; <0.001)	
SAS score for fatigue (ref. absent)			
Mild	1.60(1.40-1.83; <0.001)	0.72(0.60-0.83; <0.001)	
Moderate	0.54(0.47-0.62; <0.001)	0.73(0.62-0.86; <0.001)	<0.001*
Severe	0.75(0.66-0.86; <0.001)	0.65(0.53-0.84; 0.001)	
SAS score for pain (ref. absent)			
Mild	0.81(0.66-0.99; 0.044)	0.66(0.53-0.74; <0.001)	
Moderate	0.44(0.36-0.54; <0.001)	0.85(0.72-1.01; 0.061)	<0.001*
Severe	0.70(0.56-0.86; 0.001)	0.76(0.64-0.97; 0.111)	
PCPSS score for other symptoms (ref. absent)			
Mild	0.55(0.51-0.60; <0.001)	0.82(0.71-0.96; <0.010)	
Moderate	0.62(0.56-0.68; <0.001)	0.91(0.86-1.08; 0.277)	<0.001*
Severe	1.11(0.94-1.32; <0.206)	0.97(0.82-1.30; 0.817)	
PCPSS score for family (ref. absent)			
Mild	1.13(0.95-1.34; 0.160)	0.39(0.34-0.45; <0.001)	<0.001*

Moderate	0.59(0.50-0.69; <0.001)	0.29(0.25-0.34; <0.001)
Severe	0.55(0.46-0.65; <0.001)	0.39(0.30-0.52; <0.001)

Abbreviations: OR: odds ratios, CI: confidence interval, SEIFA: Socio-Economic Indexes for Areas, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, SAS: Symptom Assessment Scale, Ref.: reference.

NOTE. Bold indicates significant value $p < 0.05$. * Unadjusted and adjusted OR values estimated based on univariate and multivariate binary logistic regression models. Patients admitted to community palliative care services used as the reference.

† Adjusted models include all variables selected through the forward-backward stepwise procedures; unadjusted models include each specific variable.