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Symptom- and function-based trajectories of patients with dementia in hospital and community palliative care settings in the last two weeks of life: a retrospective cohort study

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Abstract

Background The prevalence of dementia is increasing worldwide and many people with the condition require some level of palliative care. However, the trajectories of function and symptom burden in palliative care services at the end of life remain unclear. This study aimed to describe and compare the longitudinal trajectories of function and symptom burden among patients with dementia between hospital versus palliative community care services in the last two weeks of life.

Methods A retrospective cohort study used data from the Australian Palliative Care Outcomes Collaboration. Patients with dementia who died between 1 January 2013 and 31 December 2020 from the Australian Palliative Care Outcomes Collaboration. Four validated clinical instruments were used to collect outcomes on each individual's function and symptom distress and severity. Multilevel models were used to estimate the differences in clinical trajectories between hospital and community-based palliative care in the last two weeks of life.

Results Patients with dementia tended to have low levels of distress for most symptoms but increasing levels of functional impairment. There were no or only marginally significant differences in the symptom trajectories between the community and hospital groups (OR ranged from 0.57 to 1.97). Although clinical trajectories of function were relatively similar between two groups, statistically higher functional indicators were observed for people when admitted to community palliative care services (OR = 0.42 and 2.27, respectively).

Conclusions Our findings suggest that community-based palliative care services can be as effective as hospital-based care for many patients with dementia nearing the end of life. With appropriate support for families, community-based care could serve as a viable alternative to hospital-based care for some patients in the final stages of dementia.

Keywords Dementia, Function, Palliative care, Symptom

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Introduction

Dementia is a general term for a condition characterized by moderate to severe cognitive and functional impairment [1]. This condition results from progressive neurodegenerative syndromes, with Alzheimer's disease being the most prevalent among them. Dementia is the seventh leading cause of mortality, and imposes substantial societal costs [2]. The global prevalence of dementia is projected to increase from 57.4 million cases in 2019 to 152.8 million by 2050 [3]. Patients with dementia have ongoing palliative care needs throughout their disease, with high-quality palliative support being especially beneficial during end-of-life care [4, 5]. Such care is commonly provided in hospitals [6, 7]. However, hospital services are under immense pressure from the rapidly rising rates of dementia, rising healthcare costs and changes in patient preferences for care at the end of life [8, 9]. Integrating palliative care into community-based settings is therefore becoming a central part of dementia management.

A 2022 scoping review of community palliative care concluded that it can reduce the disease burden for patients and carers, increase the probability of patients receiving care and/or dying in their location of choice, and reduce healthcare costs [10]. Ding et al. found that many symptom profiles may be broadly comparable for people imminently dying with dementia admitted to community palliative care services relative to those admitted to hospital services [11]. However, our previous research focused only on the time of admission to palliative care [11]. The impact of the trajectories of function and symptoms caused by disease progression on the use of different types of palliative care services remains unclear. The aim of this study was to therefore describe and compare the longitudinal trajectories of function and symptom burden in a population-based sample of people with dementia between hospital versus palliative community care services in the last two weeks of life.

Methods

A descriptive study was conducted using data from the Australian Palliative Care Outcomes Collaboration (PCOC), a national quality program funded by the Australian Government Department of Health and Aged Care [12].

Participants

The study population included people who: (1) were enrolled in palliative care services registered with PCOC; (2) needed palliative care due to a primary diagnosis of dementia, which included Alzheimer's disease and other types of dementia; (3) died between 1 January 2013 and 31 December 2020; and (4) at least one assessment was conducted as part of their palliative care within the last two weeks of life before death.

Variables

The PCOC program obtains data from patients at three linked levels. Level 1 is the patient level at which various demographic information (sex, age, preferred language, diagnosis, place of death, and days before death) is collected.

The second level is information on each 'episode of care', defined as a continuous period of care for a patient in one setting. Two different types of episodes of care, hospital- and community-based palliative care, were investigated in this study. The hospital-based palliative care encompassed patients who were seen in designated specialist palliative care units and patients in non-palliative care designated beds seen by specialist palliative care consultants/teams. The community-based palliative care included patients who received specialist palliative care at private residences or residential aged care facility. The community palliative care teams in Australia are mostly led by palliative care nurses but also include other specialists, such as social workers. They can request support from palliative care physicians when necessary.

The third level of information relates to clinical assessment outcomes at each 'phase of care,' which describes the stage/clinical condition and palliative care needs of the patient within an episode. Inpatient palliative care services conduct these assessments at admission, every 24 h 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 these 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.

Measurements

The same five standardized tools were used at each phase to assess patients' urgency of palliative care needs, function, performance, and symptom burden and severity. Clinicians assess patients' overall palliative care needs based on the holistic assessment of patients and their families using the non-sequential Palliative Care Phases (Stable, Unstable, Deteriorating, or Terminal) [13]. Inter-rater reliability of the Palliative Care Phases is substantial, with a kappa coefficient of 0.67.

Functional dependency is assessed using the Resource Utilization Groups-Activities of Daily Living (RUG-ADL)

[14]. Clinicians use the RUG-ADL to measure the motor function of patients related to bed mobility, toileting, transfers, and eating. Total scores range from 4 (independent) to 18 (needs physical assistance by two persons). The RUG-ADL achieves a 56% variance explanation for resource usage.

The Australia-modified Karnofsky Performance Status (AKPS) evaluates patients' performance relating to work, activity, and self-care [15]. The AKPS is a health professional-rated scale, ranging from 0 (deceased) to 100 (a normal function without evidence of disease), with the scores 10 to 100 captured in the PCOC dataset (as 0 signifies death). The Kappa coefficient for agreement between AKPS and the original KPS is 0.84.

The PCOC Symptom Assessment Scale (PCOC SAS) allows patients or proxies to describe the patient's level of distress relating to seven common physical symptoms (insomnia, appetite, nausea, bowels, breathing, fatigue, and pain). The symptoms are assessed on a scale of 0 to 10 (0=none;10=worst possible). The symptom distress is categorized into four levels according to the scores on PCOC SAS: none (0), mild (1 to 3), moderate (4 to 6), and severe (7 to 10). The Cronbach's alpha coefficient of PCOC SAS was 0.59 for patient ratings and 0.62 for patient and proxy ratings combined [16].

The Palliative Care Problem Severity Score (PCPSS) is a clinician-rated tool that facilitates the global assessment of four domains of palliative care: pain, psychological/spiritual, family/carer concerns, and other symptoms. Scores range from 0 (absent) to 3 (severe) with higher scores indicating higher levels of severity and difficulty to manage. The PCPSS has moderate levels of inter-rater reliability (Kappa) between 0.38 and 0.48 for the different domains [17].

Statistical methods

Stata 17.0 (Stata Corp) was used to perform all analyses. For all analyses, $p < 0.05$ was used as the level of statistical significance. Patients were removed from our analysis if they had different diagnoses regarding their type of dementia at different episodes of care. Baseline demographic and clinical characteristics of patients were summarized using frequencies or medians (with interquartile range, IQR). We conducted comparisons between the two groups (hospital versus community) using Pearson's chi-squared, Fisher's chi-squared, or Wilcoxon rank-sum test depending on the data characteristics. We described the scores on clinical assessments (RUG-ADL, AKPS, PCOC SAS, and PCPSS) using means (95% confidence interval, CI).

We performed multilevel (level 1: individual patient level; level 2: phase level) mixed-effects logistic regression to estimate the differences in symptoms and function trajectories between the hospital versus community-based groups in the last two weeks of life reporting odds ratios (ORs). The hospital group was used as the reference group. Estimates were adjusted for sex, age, diagnosis, palliative care phase, and referral source. Observations with missing values were not included in the models. We assigned RUG-ADL, AKPS, PCOC SAS, and PCPSS as categorical variables by classifying them into different clinical levels as follows: (1) for RUG-ADL: 0=monitors (corresponding to RUG-ADL=4–5), 1=requires one assistant (RUG-ADL=6–10), 2=requires one assistant plus equipment (RUG-ADL=10–15), 3=as above, pressures area risk, considers carer burden and MDT review (RUG-ADL=16–17), and 4=as above, requires two assistants; (2) for AKPS: 0=completely bedbound (AKPS=10–20), 1=increasingly limited mobility (AKPS=30–50), 2=required occasional assistance with most care needs (AKPS=60), 3=symptomatic and ambulatory (AKPS=70–80), and 4=normal activity (corresponding to AKPS=90–100); (3) for PCOC SAS: 0=clinical absent (corresponding to PCOC SAS=0–3), 1=clinical distress (PCOC SAS=4–10); (4) for PCPSS: 0=absent and mild (corresponding to PCPSS=0–1), 1=moderate to severe distress (PCPSS=2–3) [18].

Results

Study characteristics

The eligibility criteria identified 7,811 assessments in the last two weeks before death involving 5,160 patients. Patient-level characteristics revealed 2,102 (40.74%) patients in the hospital and 3,058 (59.26%) in the community, with 58.86% male patients, 51.67% aged between 85 and 94 years old, and 36.28% diagnosed with Alzheimer's dementia. Compared to hospital patients, community patients were more often female, over 85 years old, English speakers, with a longer assessment-to-death interval ($p<0.001$). Episode-level characteristics depicted 2,206 (41.61%) discrete hospital episodes and 3,096 (58.39%) community episodes, with a median length of 5 days. Community patients had longer episodes (7 days vs. 4 days) and a higher percentage of referrals from aged care facilities (46.35% vs. 1.99%). At the phase level, 3,679 (47.10%) discrete hospital phases and 4,132 (52.90%) community phases were observed, with a median length of 2 days. Community patients had longer phases before death (3 days vs. 2 days). The most common phase type was the terminal phase for both community (53.4%) and hospital groups (41.9%), followed by a deteriorating phase (34.0% vs. 38.1%; Table 1).

Symptoms and function trajectories in the last two weeks of life

Figure 1 illustrates the trajectories of mean function scores in the last two weeks of life, The mean score of RUG-ADL generally increased from 16.75 to 17.92, with

Table 1 Baseline sociodemographic and clinical characteristics for patients with dementia by episode type

Characteristics of patients	**All** ***N*****(%)**	**Hospital** ***N*****(%)**	**Community** ***N*****(%)**	***p*-value for group differences**
Total	5160	2102 (40.74)	3058(59.26)	
Sex				<0.001 [f]
Male	2122 (41.12)	1020 (48.53)	1102 (36.04)	
Female	3037 (58.86)	1081 (51.43)	1956 (63.96)	
Missing	1 (0.02)	1 (0.05)	-	
Age				<0.001 [c]
≤ 74	505 (9.79)	229 (10.90)	276 (9.02)	
75–84	1383 (26.80)	636 (30.26)	747 (24.43)	
85–94	2666 (51.67)	1049 (49.90)	1617 (52.88)	
≥95	606 (11.74)	188 (8.94)	418 (13.67)	
Diagnosis				0.98 [c]
Alzheimer's dementia	1872 (36.28)	763 (36.30)	1109 (36.27)	
Other dementia	3288 (63.72)	1339 (63.70)	1949 (63.73)	
Preferred language				<0.001 [c]
English	4412 (85.50)	1718 (81.73)	2694 (88.10)	
Non-English	748 (14.50)	384 (18.27)	364 (11.90)	
Place of death				<0.001 [f]
Home	910 (17.64)	-	908 (29.69)	
Residential Aged Care Facility	2006 (38.88)	-	1999 (65.37)	
Hospital	1098 (21.28)	1107 (52.67)	-	
Missing	1146 (22.21)	995 (47.34)	151 (4.94)	
Deaths before death				<0.001 [w]
Median (IQR)	3 (1, 6)	3 (1, 5)	4 (2, 7)	
Characteristics of episodes	**All** **N(%)**	**Hospital** **N(%)**	**Community** **N(%)**	***p*-value for group differences**
Number	5302	2206 (41.61)	3096(58.39)	
Episode length				<0.001 [w]
Median (IQR)	5 (2, 28)	4 (2, 30)	7 (3, 31)	
Referral source				<0.001 [c]
Hospital	2335 (44.04)	1782 (80.78)	553 (17.86)	
General Practitioner	817 (15.41)	28 (1.27)	789 (25.48)	
Residential Aged Care Facility	1479 (27.90)	44 (1.99)	1435 (46.35)	
Others	557 (10.71)	277 (12.56)	280 (9.04)	
Missing	114 (2.15)	75 (3.40)	39 (1.26)	
Characteristics of phases	**All** **N(%)**	**Hospital** **N(%)**	**Community** **N(%)**	***p*-value for group differences**
Number	7811	3679 (47.10)	4132(52.90)	
Phase type				<0.001 [c]
Stable	530 (6.79)	222 (6.03)	308 (7.45)	
Unstable	442 (5.66)	313 (8.51)	129 (3.12)	
Deteriorating	2679 (34.30)	1198 (32.56)	1481 (35.84)	
Terminal	4160 (53.26)	1946 (52.89)	2214 (53.58)	
Phase length				<0.001 [w]
Median (IQR)	2 (1, 4)	2 (1, 3)	3 (1, 6)	

Abbreviations: IQR, interquartile range; c, Chi-square tests; w, Wilcoxon rank-sum test; f, Fisher Chi-square test

hospital patients having generally higher scores. AKPS decreased from a mean of 26.55 to 13.45, with the community group initially having higher scores. Figure 2 shows that less than one fifth of patients measured by the PCOC SAS experienced moderate-to-severe distress, with mean scores below 2 for all individual symptoms (Figure S1). Fatigue and appetite decreased, while breathing problems increased as death approached. Hospital patients exhibited higher variability in more than half of the symptoms, while had similar percentage of moderate-to-severe distress as community patients. Figure 3 displays less than two-fifths of patients in both groups experiencing moderate-to-severe distress according to the PCPSS, with mean scores consistently below

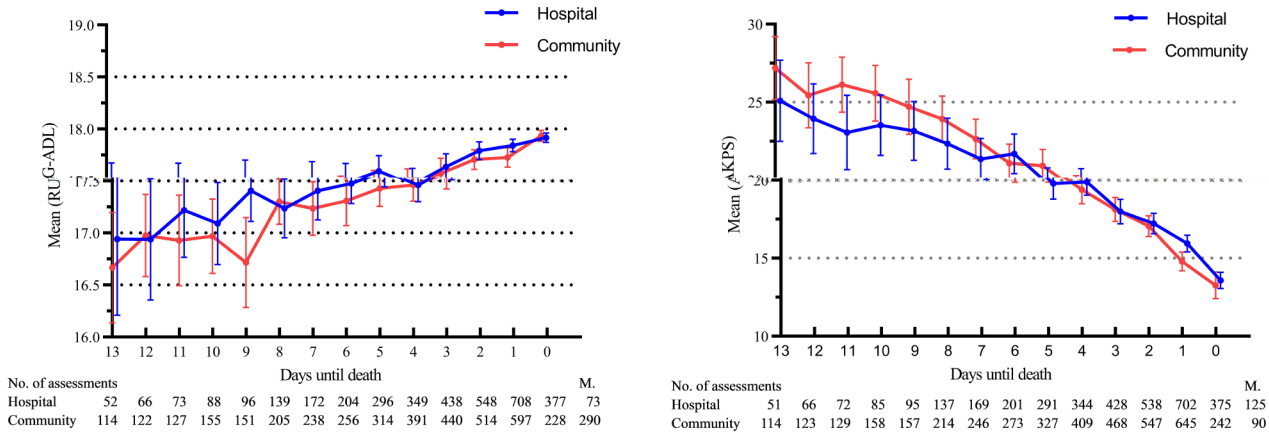

Fig. 1 Mean scores and 95%CI of Resource Utilization Groups-Activities of Daily Living (RUG-ADL) and Australia modified Karnofsky Performance Score (AKPS) in the last two weeks of life. M., missing

1.5 (Figure S1). The psychological/spiritual domain had relatively lower mean scores and percentages in both groups. Patients in the community reported lower distress percentages in most domains compared to the hospital group.

Comparisons of function and symptoms trajectories between the two groups

Tables 2 and 3 show the adjusted ORs for trajectories of clinical assessments between the two groups in the last two weeks of life. For indicators of function, community patients have significantly lower odds for RUG-ADL (OR=0.42, 95% CI: 0.28–0.62) and higher odds for AKPS (OR=2.27, 95% CI: 1.57–3.28) compared to hospital patients, reflecting superior functional outcomes in the community setting during the corresponding period. For symptom-related variables, the community group had comparable levels for more than half of the symptom-related variables. The exceptions were PCOC SAS bowels (OR=1.52, 95% CI: 1.10–2.08), PCOC SAS insomnia (OR=1.79, 95% CI: 1.27–2.53), PCPSS pain (OR=0.57, 95% CI: 0.43–0.74), PCPSS psychological/spiritual (OR=0.66, 95% CI: 0.49–0.89), and PCPSS family/carer concerns (OR=1.97, 95% CI: 1.51–2.58), indicating that higher levels of PCPSS pain and psychological/spiritual issues were observed in hospital settings, while bowel, insomnia, and family/carer concerns were higher in the community.

Trajectory trends revealed decreases in AKPS (OR=0.82, 95 CI%: 0.79–0.85), PCOC SAS fatigue (OR=0.95, 95 CI%: 0.91–0.99), and PCOC SAS insomnia (OR=0.96, 95 CI%: 0.92–0.99) on each day closer to death, whereas an increasing trend was observed for RUG-ADL (OR=1.21, 95 CI%: 1.15–1.26) and PCOC SAS breathing (OR=1.33, 95 CI%: 1.19–1.45). It was observed that each day closer to death brought a decline in functional abilities, fatigue and insomnia, while breathing difficulties showed a rise.

Using patients under 75 years as a reference, there were decreased odds in AKPS for the age group of 85–94 years (OR=0.49, 95%CI: 0.30–0.79), PCOC SAS breathing across all older age groups (ORs ranging from 0.38 to 0.53), PCPSS family/carer concerns for the age groups of 85–94 years (OR=0.36, 95%CI 0.23–0.56) and above 95 years (OR=0.61, 95%CI: 0.44–0.85), and PCPSS other symptoms for the 85–94 years age group (OR=0.71, 95% CI: 0.23–0.56, 0.51–0.98). Being female was associated with higher odds for RUG-ADL, PCOC SAS nausea, and PCOC SAS pain (OR ranging from 1.30 to 2.78), and lower odds for AKPS and PCPSS other symptoms (OR ranging from 0.63 to 0.80). The results demonstrated that female had worse functional outcomes, PCOC SAS pain, and other symptoms. Using Alzheimer's dementia as the reference group, patients with other types of dementia tended to have lower odds for RUG-ADL (OR=0.56, 95% CI: 0.41–0.77), suggesting that poorer functional performance. Compared with the assessments in the stable phase, significantly higher odd ratios for most clinical measures were observed during unstable, deteriorating, or terminal phases. Compared to patients referred from the hospital, significantly higher odds ratios were observed in nearly half of clinical measures for patients from general practitioners and residential aged care facilities.

Discussion

The results showed that, overall, patients with dementia receiving palliative care tended to have low levels of distress for the majority of symptoms but relatively increased levels of breathing distress and functional impairment in their last week of life. When considering the effect of different palliative care settings, there were no or only marginally significant differences in the

Fig. 2 The percentage of moderate-to-severe categories as assessed by the Symptoms Assessment Scale (PCOC SAS) in the last two weeks of life. M., missing

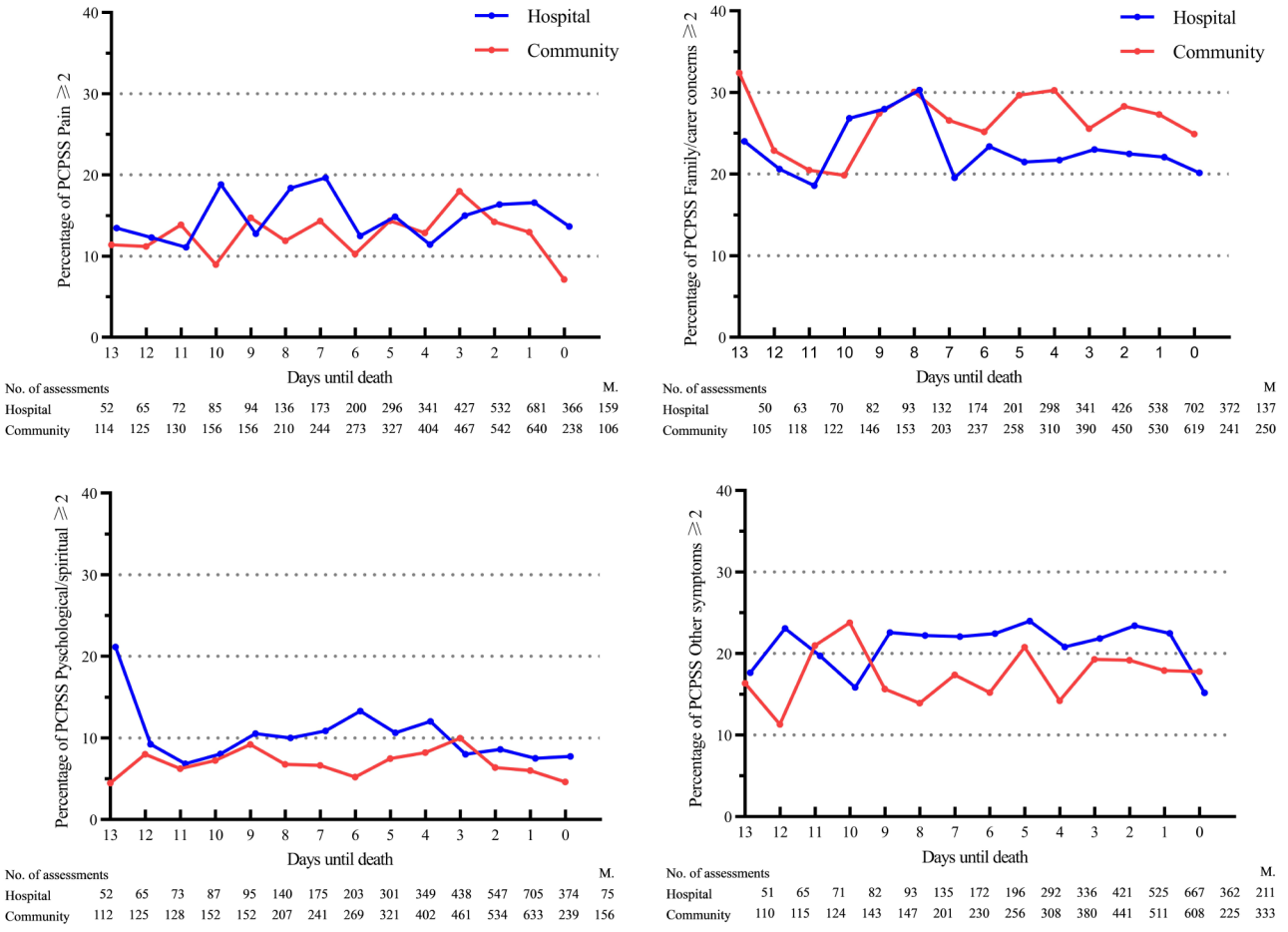

Fig. 3 The percentage of moderate-to-severe categories as assessed by the Palliative Care Problem Severity Score (PCPSS) in the last two weeks of life. M., missing

symptom trajectories between the community and hospital groups. Although clinical trajectories of function were relatively similar between two groups, statistically higher functional indicators were observed for people when admitted to community palliative care services.

The relatively low levels of symptom distress observed for most people with dementia contrasts with the commonly-held view that symptom intensity increases at end-of-life for most chronic and progressive medical disorders [19–21]. This finding suggests that, in most cases, the symptom severity did not markedly escalate for patients with late-stage dementia while managed in hospital and community palliative care settings [22].

Unlike other major symptoms assessed, breathing problems increased in this cohort as death approached. Previous studies of patients referred to palliative care have noted that the prevalence of breathlessness increases rapidly towards the end of life [23]. Changes in clinical trajectories can also be seen in the functional burden, which is in line with previous studies of palliative care patients, including those with dementia [24]. Accelerating deterioration in physical function are not only a prognostic indicator for end-of-life for patients, but also signal the likely need for palliative care [25]. Prior literature consistently reported that people with dementia presented with higher levels of functional impairment and needed more assistance with basic activities of daily living in comparison with patients with other life-limiting conditions [24, 26].

This study compared the clinical trajectories for patients with dementia in different palliative care settings. In relation to functional outcomes, community patients had significantly better function than hospital patients in the last two weeks. This finding is comparable to those of previous studies, where higher levels of dependency and lower functional performance were associated with increased hospitalizations [27]. As patients exhibit difficult-to-treat functional loss, family caregivers often experience difficulties in coping and are more likely to seek hospital-based support [28, 29].

The symptoms were assessed based on PCPSS and SAS. Hospital patients with dementia displayed a higher

Table 2 Odds ratios of RUG-ADL, AKPS, and PCPSS for patients with dementia in the last two weeks end of life

	RUG-ADL	AKPS	PCPSS			
			Pain	Psychological/spiritual	Family/carer concerns	Other symptoms
	OR (95% CI; *p*-value)					
Episode type						
Hospital (Ref.)						
Community	**0.42 (0.28–0.62; < 0.001)**	**2.27 (1.57–3.28; < 0.001)**	**0.57 (0.43–0.74; < 0.001)**	**0.66 (0.49–0.89; 0.01)**	**1.97 (1.51–2.58; < 0.001)**	0.77 (0.59–1.00; 0.05)
Time: Time interval between first assessment and death (day 13 to 0)	**1.21 (1.15–1.26; < 0.001)**	**0.82 (0.79 - 0.85; < 0.001)**	0.99 (0.93–1.06; 0.76)	1.02 (0.98–1.05; 0.34)	0.97 (0.93–1.01; 0.20)	0.98 (0.93–1.03; 0.34)
Covariates						
Age group						
≤74 (Ref.)						
75–84	1.01 (0.58–1.74; 0.97)	0.73 (0.53–1.01; 0.06)	0.94 (0.67–1.33; 0.75)	0.78 (0.53–1.14; 0.20)	0.70 (0.50–0.99; 0.05)	0.73 (0.52–1.03; 0.07)
85–94	0.93 (0.56–1.54; 0.77)	**0.49 (0.30–0.79; < 0.001)**	1.03 (0.75–1.41; 0.88)	0.77 (0.54–1.09; 0.14)	**0.61 (0.44–0.85; < 0.001)**	**0.71 (0.51–0.98; 0.04)**
≥95	0.77 (0.41–1.45; 0.42)	0.87 (0.57–1.34; 0.54)	0.91 (0.61–1.37; 0.66)	0.80 (0.51–1.26; 0.34)	**0.36 (0.23–0.56; < 0.001)**	0.67 (0.44–1.02; 0.06)
Sex						
Male (Ref.)						
Female	**1.57 (1.16–2.13; < 0.001)**	**0.63 (0.48–0.83; < 0.001)**	**1.30 (1.07–1.58; 0.01)**	1.03 (0.83–1.28; 0.80)	0.96 (0.78–1.17; 0.65)	**0.80 (0.65–0.97; 0.02)**
Diagnosis						
Alzheimer (Ref.)						
Other dementia	**0.56 (0.41–0.77; < 0.001)**	1.20 (0.91–1.59; 0.19)	1.09 (0.90–1.32; 0.37)	1.22 (0.98–1.53; 0.08)	0.90 (0.73–1.10; 0.29)	0.99 (0.81–1.21; 0.95)
Phase type						
Stable (Ref.)						
Unstable	1.31 (0.83–2.06; 0.24)	1.02 (0.66–1.57; 0.93)	**11.35 (6.52–19.75; < 0.001)**	**5.28 (3.03–9.22; < 0.001)**	**9.75 (5.81–16.34; < 0.001)**	**15.66 (9.17–26.76; < 0.001)**
Deteriorating	**2.41 (1.69–3.43; < 0.001)**	**0.43 (0.31–0.6; < 0.001)**	**4.04 (2.49–6.56; < 0.001)**	**2.30 (1.45–3.65; < 0.001)**	**4.07 (2.67–6.18; < 0.001)**	**4.27 (2.75–6.64; < 0.001)**
Terminal	**30.42 (18.88–49.03; < 0.001)**	**0.01 (0–0.01; < 0.001)**	**2.41 (1.48–3.91; < 0.001)**	1.05 (0.65–1.68; 0.84)	**2.59 (1.70–3.95; < 0.001)**	**1.96 (1.26–3.04; < 0.001)**
Referral source						
Hospital (Ref.)						
General Practitioner	**0.54 (0.33–0.88; 0.01)**	0.96 (0.60–1.52; 0.85)	**2.01 (1.43–2.81; < 0.001)**	**1.56 (1.07–2.28; 0.02)**	1.01 (0.72–1.41; 0.98)	1.07 (0.76–1.50; 0.70)
Residential Aged Care Facility	**2.84 (1.78–4.55; < 0.001)**	**2.52 (1.67–3.79; < 0.001)**	**2.01 (1.48–2.73; < 0.001)**	1.27 (0.90–1.81; 0.18)	**0.68 (0.50–0.92; 0.01)**	1.11 (0.82–1.50; 0.51)
Others	0.74 (0.46–1.19; 0.22)	0.82 (0.52–1.29; 0.39)	**1.41 (1.03–1.91; 0.03)**	1.29 (0.92–1.80; 0.14)	**1.47 (1.07–2.01; 0.02)**	**1.38 (1.01–1.88; 0.04)**
Missing	0.47 (0.20–1.08; 0.08)	1.17 (0.53–2.63; 0.70)	1.06 (0.53–2.13; 0.86)	0.60 (0.25–1.40; 0.24)	0.89 (0.42–1.89; 0.76)	1.04 (0.54–2.02; 0.90)

Note: Bold indicates the significant value of $p<0.05$.

Abbreviations: AKPS: Australian-modified Karnofsky Performances Status, RUG-ADL: Resource Utilisation Group-Activities for Daily Living, PCPSS: Palliative Care Problem Severity Score, CI: confidence interval

Table 3 Odds ratios of PCOC SAS for patients with dementia in the last two weeks end of life

	Nausea	Fatigue	Bowels	Appetite	Insomnia	Pain	Breathing
				OR (95% CI; *p*-value)			
Episode type							
Hospital (Ref.)							
Community	0.59 (0.28–1.23; 0.16)	1.02 (0.70–1.50; 0.90)	**1.52 (1.10–2.08; 0.01)**	1.52 (0.99 - 2.33; 0.05)	**1.79 (1.27–2.52; < 0.001)**	0.99 (0.77–1.27; 0.94)	1.08 (0.72–1.64; 0.70)
Time: Time interval between first assessment and death (day 13 to 0)	1.01 (0.82–1.23; 0.96)	**0.95 (0.91–0.99; 0.02)**	1.02 (0.98–1.06; 0.30)	0.96 (0.88 - 1.04; 0.35)	**0.96 (0.92–0.99; 0.02)**	1.03 (1.00–1.07; 0.07)	**1.33 (1.19–1.45; < 0.001)**
Covariates							
Age group							
≤74 (Ref.)							
75–84	2.30 (0.69–7.66; 0.17)	0.77 (0.47–1.27; 0.31)	0.98 (0.64–1.50; 0.93)	1.10 (0.61–1.97; 0.75)	0.95 (0.59–1.53; 0.85)	0.98 (0.71–1.37; 0.93)	**0.53 (0.32–0.89; 0.02)**
85–94	2.88 (0.91–9.12; 0.07)	0.71 (0.44–1.14; 0.15)	0.78 (0.52–1.16; 0.22)	1.02 (0.59–1.77; 0.08)	1.02 (0.66–1.59; 0.91)	0.98 (0.72–1.33; 0.89)	**0.47 (0.29–0.76; < 0.001)**
≥95	1.40 (0.35–5.58; 0.63)	0.80 (0.44–1.44; 0.46)	0.96 (0.58–1.58; 0.88)	1.16 (0.60–2.29; 0.65)	1.00 (0.58–1.74; 0.99)	0.83 (0.56–1.24; 0.37)	**0.38 (0.20–0.73; < 0.001)**
Sex							
Male (Ref.)							
Female	**2.78 (1.55–5.00; < 0.001)**	0.98 (0.74–1.30; 0.88)	1.06 (0.83–1.35; 0.63)	1.30 (0.94 - 1.90; 0.12)	0.96 (0.74–1.25; 0.76)	**1.36 (1.13–1.65; < 0.001)**	0.80 (0.59–1.10; 0.17)
Diagnosis							
Alzheimer (Ref.)							
Other dementia	1.33 (0.78–2.26; 0.29)	1.15 (0.86–1.53; 0.36)	1.04 (0.81–1.33; 0.74)	0.96 (0.70 - 1.33; 0.82)	1.20 (0.92–1.58; 0.17)	1.13 (0.94–1.37; 0.2)	0.94 (0.69–1.28; 0.68)
Phase type							
Stable (Ref.)							
Unstable	**4.44 (1.50–13.12; 0.01)**	**4.88 (2.72–8.74; < 0.001)**	**2.25 (1.29–3.92; < 0.001)**	**5.29 (2.70 - 10.36; < 0.001)**	**6.63 (3.58–12.28; < 0.001)**	**12.7 (7.63–21.14; < 0.001)**	**8.32 (3.26–21.25; < 0.001)**
Deteriorating	1.48 (0.58–3.76; 0.41)	**2.50 (1.58–3.97; < 0.001)**	1.40 (0.90–2.18; 0.14)	**2.36 (1.38 - 4.04; < 0.001)**	**2.66 (1.59–4.44; < 0.001)**	**3.37 (2.18–5.20; < 0.001)**	**2.97 (1.32–6.69; 0.01)**
Terminal	0.53 (0.19–1.47; 0.23)	**0.47 (0.27–0.80; 0.01)**	**0.49 (0.31–0.77; < 0.001)**	**0.31 (0.17 - 0.58; < 0.001)**	0.68 (0.40–1.16; 0.16)	**2.09 (1.34–3.24; < 0.001)**	1.92 (0.85–4.33; 0.12)
Referral source							
Hospital (Ref.)							
General Practitioner	**2.58 (1.08–6.16; 0.03)**	**2.16 (1.33–3.54; < 0.001)**	0.75 (0.50–1.13; 0.17)	1.68 (1.00 - 2.81; 0.05)	1.02 (0.66–1.56; 0.94)	**1.56 (1.14–2.14; 0.01)**	1.40 (0.84–2.34; 0.20)
Residential Aged Care Facility	1.65 (0.70–3.86; 0.25)	1.45 (0.94–2.23; 0.10)	0.76 (0.52–1.09; 0.14)	0.74 (0.46 - 1.21; 0.23)	**0.58 (0.39–0.86; 0.01)**	**1.63 (1.22–2.16; < 0.001)**	0.77 (0.47–1.25; 0.29)
Others	1.48 (0.68–3.20; 0.32)	**1.8 (1.14–2.83; 0.01)**	1.32 (0.92–1.91; 0.14)	1.28 (0.77 - 2.12; 0.34)	0.78 (0.51–1.19; 0.25)	1.21 (0.90–1.64; 0.21)	0.81 (0.49–1.33; 0.41)
Missing	-	0.72 (0.25–2.08; 0.54)	1.12 (0.43–2.94; 0.81)	0.49 (0.14 - 1.74; 0.27)	1.09 (0.41–2.89; 0.86)	1.26 (0.61–2.60; 0.54)	0.60 (0.14–2.61; 0.50)

Note: Bold indicates the significant value of $p<0.05$; - indicates an empty field

Abbreviations: SAS: Symptom Assessment Scale, CI: confidence interval

degree of variability (more and/or a greater fluctuation) across their admission for more than half of symptoms assessed by the SAS. It means that specialized hospital management should be available for all patients with complex or urgent palliative care needs where required [30]. However, the community group experienced similar or even lower levels of distress on the majority of symptoms when compared to the hospital group. One possible explanation might be the familiar care provided by the carers in these settings [31]. Often, patients in community settings benefit from being looked after by a relatively stable team of caregivers who have developed a strong rapport with them over time. This familiarity may foster a sense of comfort and trust, which could contribute to lower levels of reported distress.

Higher levels of PCPSS family/carer problems were noted for patients receiving community-based palliative care relative to hospital. This result aligns with a previous study [32], and likely relates to the increased burden experienced by families caring for their loved one in the community as s/he deteriorates, whereas families of hospitalized patients are not as exposed to this added burden. For the other PCPSS domains, community-based groups had comparable and even better scores compared to hospital. Despite an acknowledged lack of skilled staff and resources in community palliative care in Australia [33], these results indicate that patients with dementia who are nearing the end of life in the community may be receiving symptom support comparable to that provided to hospital.

Notable differences in sociodemographic and clinical characteristics were also observed between community and hospital patients in this study. For sociodemographic factors, the greater prevalence of female patients in the community compared to hospitals. This may be linked to men's expectations about 'faint hopes' of a cure, while women looked to the continuity of long-term relationships with community settings as a source of support [34]. Then, older age in community patients can be attributed to the fact, compared to relatively younger patients, older people want to be cared for and to die in the familiar surroundings of their own home [35]. Additionally, community patients were more likely to be English speakers might indicate that language proficiency can impact patients' ability to navigate the healthcare system and receive care [36].

For the clinical characteristics, community patients had extended assessment-to-death intervals, prolonged episodes, and longer phases before death, along with a significantly higher percentage of referrals from aged care facilities. Specifically, community-based care often involves a more gradual and continuous approach, prioritizing the respect for personal value and maintaining comfort over an extended period [37]. This might result in prolonged intervals, episodes, and phases as caregivers strive to manage symptoms and provide holistic support [38]. In contrast, hospital settings typically have immediate access to more intensive medical treatments, aligning with the symptom trajectories evaluated by SAS. Additionally, the longer phase could also be attributed to the different assessment approaches across settings. In community care, assessments are made only at each point of contact, whereas hospitals perform assessments every day. Regarding the differences in referral sources across settings, it may be shaped by the care continuity [39]. Aged care facilities frequently have strong connections with community palliative care providers, facilitating smooth transitions to local palliative care services. Conversely, hospital-based palliative care teams typically intervene when a patient's symptoms worsen during a hospital stay, resulting in a higher rate of internal referrals.

This study had a number of limitations. First, community palliative care in our study involved patients who lived in both a private residence and residential aged care facilities. People living in residential aged care facilities may have a different symptom and function profile to people living in private residences and we were unable to distinguish these sub-groups in our study. Further research to explore any gaps between home and residential aged care facilities is needed. Furthermore, our study focuses primarily on end-stage dementia, but the absence of comorbidities may introduce variability in our data, potentially impacting the generalizability of our results. Future research should include broader comprehensive data to better elucidate their effects on end-of-life care and outcomes. Next, we acknowledge that the limited longitudinal follow-up in our study introduces certain challenges in interpreting the trajectories presented. The relatively small number of patients with complete follow-up limits the generalizability of these trajectories. Consequently, while these trajectories provide valuable insights, they should be interpreted with caution, taking into account the potential selection bias.

Conclusion

This large observational study provides valuable insights into the function and symptom trajectories of patients with dementia receiving palliative care in their last two weeks of life. This study has important implications for the need for targeted interventions to address increasing distress related to breathing difficulties and functional impairment. Additionally, our findings advocate for the consideration of community-based palliative care services as a viable alternative to hospital-based care for patients with dementia, provided that adequate support is available for families and caregivers.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-024-01565-6.

Supplementary Material 1

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Study concept and design: Jinfeng Ding, Angus Cook, and Claire E Johnson. Acquisition of data: Jinfeng Ding, Angus Cook, and Claire E Johnson. Analysis and interpretation of data: Minghui Tan. Drafting of the manuscript: Minghui Tan. Critical revision of the manuscript for important intellectual content: Jinfeng Ding, Angus Cook, Xiwen (Simon) Qin, Lin Xiao, Juan Wang, and Claire E Johnson.

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Data availability
The data that were used for this study are available upon reasonable request from the Palliative Care Outcomes Collaboration. Requests can be made through the application form which can be found at: https://www.uow.edu.au/ahsri/pcoc/.

Declarations

Ethics approval and consent to participate
The study was conducted in accordance with the Declaration of Helsinki. The PCOC program has been approved by the Human Research Ethics Committee (HREC) of the University of Wollongong (2021/ETH00988). This study was based on a secondary analysis of PCOC data and an exemption from ethics review was approved by the Human Ethics office at the University of Western Australia (RA/4/20/6280). All participants gave informed consent and their anonymity was preserved.

Consent for publication
Not applicable.

Authors consent
All authors had approved the final article.

Competing interests
The authors declare no competing interests.

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