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Palliative care needs and utilization of specialist services for people diagnosed with motor neurone disease: A national population-based study

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Palliative care needs and utilization of specialist services for people diagnosed with motor neurone disease: A national population-based study

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Abstract

Introduction: There is a growing emphasis on the importance of the availability of specialist palliative care for people with motor neurone disease (MND). However, the palliative care needs and utilization of different specialist services of this population remain poorly defined.

Objectives: To (i) compare clinical characteristics, symptom burden and functional levels of patients dying with MND upon their admission to palliative care services; (ii) determine how these care needs affect their utilization of different palliative care services.

Design: An observational study based on point-of-care data from the Australian Palliative Care Outcomes Collaboration (PCOC).

Participants: A total of 1,308 patients received palliative care principally because of MND between 1 January 2013 and 31 December 2020.

Measures: Five validated clinical instruments were used to assess each individual's function, distress from symptoms, symptom severity and urgency and acuity of their condition.

Results: Most MND patients had no or mild symptom distress, but experienced a high degree of functional impairment. patients who "require two assistants for full care" relative to those who are "independent" (odds ratio = 11.73, 95% confidence interval:

4.98–27.62) and those in “unstable” relative to “stable” palliative care phases (odds ratio =15.95, 95% confidence interval: 7.43– 34.27) were more likely to use inpatient rather than community-based palliative care. Associations between the use of different palliative care services and levels of symptom distress were not observed in this study.

Conclusions: More patients with MND primarily needed assistance for decreased function and activities of daily living, rather than symptom management. This population could have potentially been cared for in the palliative phase in a community setting if greater access to supportive services had been available in this context.

Keywords

palliative care, motor neuron disease, symptoms, function, Health Services

Strengths and limitations of this study

⇒ A major strength of this study lies in its large sample size, which was based on national population data.

⇒ This is the first large-scale national study to comprehensively examine the clinical characteristics and care needs of palliative care patients with motor neurone disease in Australia.

⇒ The data of this study spans a relatively long time series, including death cases that occurred from 2013 to 2020.

⇒ The limitation of this study is that the PCOC system (the data source of this study) may not capture information on particular patient characteristics and clinical needs that may influence their utilization of different types of palliative care services.

Introduction

Motor neurone disease (MND) is a neurodegenerative condition that progressively affects the brain and spinal cord, ultimately leading to a locked-in state[1,2]. In Australia, it is estimated that approximately 2,100 individuals are living with MND[3] and on average, two people die each day from MND[4]. The average life expectancy varies and can range from two to five years or longer, depending on the severity and muscle groups affected by the disease[5]. As the illness progresses, many people living with MND experience a wide range of constantly changing care needs[1]. The UK's National Service Framework for Long-Term Conditions advocates life-long care for people diagnosed with long-term neurological conditions (LTNC) - including MND - and recommends an integrated approach involving neurology, rehabilitation, and palliative care to address the diagnostic, restorative, and palliative phases of illness[6].

Palliative care is generally defined as a multidisciplinary care approach to improve the quality of life for individuals facing life-limiting conditions and their families[7]. In recent years, there has been a growing recognition of the need for palliative care to be made available to all patients nearing the end of life, irrespective of their diagnosis, including those affected by MND[8]. Extensive research has shown the value of palliative care for people diagnosed with MND in alleviating clinical symptoms such as pain, dyspnea, sleep disturbances, and bowel symptoms, as well as improving the quality of life for both patients and their families[9–12]. However, non-malignant diseases such as MND are still under-represented in palliative care[13]. Although various palliative care strategies have been formulated, their applicability to people with MND is limited due to the unique palliative care requirements and disease trajectory [14]. Therefore, there is a need to optimize palliative care for people with MND by providing the 'right care in the right place at the right time'.

Palliative care in Australia is recognized internationally for its quality and accessibility[15]. Community-based palliative care (CPC) and inpatient palliative care (IPC) services are two essential settings of care that have different processes and structures, resourcing and both are critical in providing palliative care[16]. Depending on their specific needs, social and clinical characteristics, either CPC or IPC may be appropriate for different patients at any given time. Although there is increasing awareness of the role of palliative care for people diagnosed with neurological disorders[11], and specifically for those with MND[10,12,17], there is little evidence on how patients' needs affect the utilization of different specialist services during the last few days of life. Such knowledge would enable the evaluation of whether individuals dying with MND receive the 'right care in the right place' and would also enhance care, inform policy development, resource allocation, and personnel training. This study aimed to (a) describe and compare the symptom burden and level of function of people with MND on their final admission to IPC and CPC before death, and (b) determine whether and how care needs and other clinical factors related to the use of different specialist palliative care services.

Methods

Study design and data sources

De-identified, point-of-care data were collected by the Australian Palliative Care Outcomes Collaboration (PCOC) [18], a voluntary national program focused on improving the quality and outcomes in palliative care. The PCOC program, which is funded by the Australian Government

Department of Health and Aged Care, evaluates patients in inpatient and community settings across various models of care. Its data set captures demographic, setting, and clinical assessment information for palliative care patients. Inpatient palliative care services conduct detailed assessments of individual patients upon admission and then at least daily and at phase change. Community palliative care services perform assessments on admission and during each subsequent encounter (e.g. each visit), in-person or by telephone/telehealth [19]. Data related to admission, phase changes, and discharge are reported to PCOC biannually. Before data are analysed, the PCOC program conducts a review and data cleaning process. Participating services receive six-monthly reports on their performance which allows comparisons with national results and performance benchmarks established against industry standards.

Patient and public involvement

There was no direct patient or public involvement in this study.

Variables and instruments

Five validated clinical instruments were used to assess clinical outcomes[18]. Levels of distress from symptoms (i.e. difficulties with sleeping, appetite, nausea, bowel symptoms, breathing problems, fatigue, and pain) were assessed using the 11-point Symptoms Assessment Scale (PCOC SAS) (0 – absent; 10 – worst possible)[20]. The PCOC SAS is ideally rated by the patient, but rating by proxies (i.e. family or clinicians) is permitted if the patient loses the capacity of self-assessment. The severity of patients' palliative care problems (pain, other symptoms, psychological/spiritual, and family/career concerns) were evaluated using the clinician-rated, four-point Palliative Care Problem Severity Score (PCPSS) (0–absent; 3–severe)[21]. Patients' level of functional dependency (eating, toileting, bed mobility, and transfers) were rated using the Resource Utilisation Groups - Activities of Daily Living (RUG-ADL), which scores eating based on a three-point item (1–independent or supervision only; 3–total dependence/tube fed), and the other three activities (toileting, bed mobility, and transfers) with five-point items (1–independent; 5–two or more persons assist)[22]. Performance status was determined by the 11-point Australia-modified Karnofsky Performance Status (AKPS) (0–dead; 100–complete function)[23]. The non-sequential Palliative Care Phase (Stable, Unstable, Deteriorating, or Terminal) is a holistic assessment of patients and their carers (including families) palliative needs and concerns[24]. The latter four of the tools were designed to be rated by trained clinicians.

Other clinical and socio-demographic characteristics involved in the study included length of palliative care stay, referral source, accommodation at the start of the episode and place of death. A summary measure of social and economic conditions, the Socio-Economic Indexes for Areas (SEIFA) [25], was also included. This indicator, developed by the Australian Bureau of Statistics, ranks areas in Australia according to relative socio-economic advantage and disadvantage, with scores ranging from 1 (very high levels of disadvantage) to 10 (very low levels of disadvantage).

This study focused on the first assessment conducted on admission to the inpatient or community care setting that is during their first episode of care for each patient. The term 'episode of care' is defined as a continuous period of care for a patient in one setting.

Population and setting

This study included patients who met the following criteria: (i) required specialist palliative care from one or more of the services across Australia registered in PCOC; (ii) required palliative care principally for MND; (iii) with a first episode of care occurring between 1 January 2013 and 31 December 2020; and (iv) death occurring between 1 January 2013 and 31 December 2020. Two types of specialist palliative care episodes were included in this study: community and inpatient (including consult liaison services). An ‘inpatient episode’ refers to patients who have been seen in designated specialist palliative care units as well as in non-palliative care designated beds by specialist palliative care consultants/teams. A ‘community episode’ refers to people who received specialist palliative care at private residences or residential care facilities[18].

Data analysis

Characteristics of participants and episodes were described using frequency and percentages. Standard clinical measures (RUG-ADL, AKPS, PCPSS, and SAS) were presented using means (standard deviation, SD) and medians (with interquartile range, IQR). Differences between the two types of specialist palliative care episodes (community and inpatient) were assessed using Pearson’s chi-square tests (characteristics of participants and episodes) and Mann–Whitney U tests (length of stay and standard clinical measures)

Multivariable logistic regression analyses were conducted to test whether and how clinical characteristics affected the utilization of inpatient versus community palliative care services. The multicollinearity of the model was assessed using variance inflation factors (VIF). Significant associated factors of different specialist services utilization were determined by using stepwise procedures. In our multivariate models, inclusion and exclusion criteria were set at significance levels of 0.05 and 0.10, respectively. We also utilized C-index to assess the fitness of the final model. Due to the high level of correlation within elements of the RUG-ADL family, we only selected “Total RUG-ADL” for the stepwise procedures. *P*-values for the trend of the following variables were calculated: age, days until death, and scores of symptoms and function. Patients receiving community services were used as the reference group.

In the regression analyses, PCOC SAS, PCPSS, total RUG-ADL, and AKPS were coded as categorical variables based on different clinical levels as follows: (i) Scores on PCOC SAS were classified as: 0 = absent (corresponding to PCOC SAS = 0), 1 = mild (PCOC SAS = 1–3), 2 = moderate to severe (PCOC SAS = 4–10); (ii) PCPSS was classified as follows: for PCPSS: 0 = absent (corresponding to PCPSS = 0), 1 = mild (PCPSS = 1), 2 = moderate to severe (PCPSS = 2–3); (iii) for AKPS: 1 = ambulatory > 50% of the time (corresponding to AKPS = 50–100), 2 = largely impaired mobility (AKPS = 30–40), 3 = bedridden (AKPS = 10–20). (iv) for RUG-ADL: 1 = independent (corresponding to total RUG-ADL = 4–5), 2 = limited physical assistance (total RUG-ADL = 6–13), 3 = requires one assistant plus equipment (total RUG-ADL = 14–17), 4 = requires two assistants for full care (total RUG-ADL = 18).

We fitted Kaplan-Meier curves and performed log-rank tests to compare survival time after admission between the two groups. Survival time was defined as the time interval between the date of first admission to a palliative care service to the date of death with a censor date of 31 December 2020.

Descriptive statistic estimation, logistic regression analyses, and collinearity analysis were performed using SPSS 26.0. The C-index and Kaplan-Meier curves were estimated using R statistical software version 4.0. *P*-values < 0.05 were considered statistically significant.

Results

Study population

A total of 1,308 people with MND were included in this study with 56.4% (738) accessing palliative care in a community setting and 43.6% (570) in an inpatient setting. A total of 54.4% were male, 34.9% were <65 years of age and 92.7% were from English-speaking families. More than 50% lived in areas with SEIFA category > 6. There were no statistically significant differences between the two groups for these sociodemographic characteristics.

Table 1 Baseline sociodemographic and clinical characteristics for people with MND by episode settings

Characteristics of Patients	**All N (%)**	**Community *N* (%)**	**Inpatient *N* (%)**	***p*-values for differences by setting**
Sociodemographic characteristics				
Total number	1308	738(56.4)	570(43.6)	-
Sex				
Male	712(54.4)	417(56.5)	295(51.8)	0.087
Female	596(45.6)	327(43.5)	275(48.2)	
Age				
< 65 years	457(34.9)	264(35.8)	193(33.9)	0.472
≥ 65 years	851(65.1)	474(64.2)	377(66.1)	
Preferred language				
English	1212(92.7)	682(92.4)	530(93.0)	0.695
Non-English	96(7.3)	56(7.6)	40(7.0)	
SEIFA				
1-2	183(14.0)	104(14.1)	79(13.9)	0.994
3-4	143(11.0)	79(10.7)	64(11.2)	
5-6	225(17.2)	128(17.4)	97(17.1)	
7-8	324(24.8)	181(24.5)	143(25.2)	
9-10	431(33.0)	246(33.3)	185(32.6)	
Characteristics of Episodes of Care				
Years of admission				
2013	127(9.7)	64(8.7)	63(11.1)	0.202
2014	121(9.3)	62(8.4)	59(10.3)	
2015	150(11.5)	81(11.0)	69(12.1)	
2016	187(14.3)	102(13.8)	85(14.9)	
2017	186(14.2)	116(15.7)	70(12.3)	
2018	198(15.1)	113(15.3)	85(14.9)	
2019	202(15.4)	126(17.1)	76(13.3)	
2020	137(10.5)	74(10.0)	63(11.1)	
Referral source				
Hospital	468(35.8)	215(29.1)	253(44.4)	**<0.001**
Community service	556(42.5)	311(42.1)	245(43.0)	
Others	86(6.6)	75(10.2)	11(1.9)	
Missing	198(15.1)	137(18.6)	61(10.7)	
Accommodation at the start of episode				
Private residence	1035(79.1)	616(83.5)	419(73.5)	**<0.001**
Residential aged care	116(8.9)	85(11.5)	31(5.4)	
Other	36(2.7)	22(3.0)	14(2.5)	
Missing	121(9.3)	15(2.0)	106(18.6)	
Phase type on admission				
Stable	393(30.0)	303(41.1)	90(15.8)	**<0.001**
Unstable	255(19.5)	26(3.5)	229(40.2)	
Deteriorating	588(45.0)	395(53.5)	193(33.8)	
Terminal	72(5.5)	14(1.9)	58(10.2)	
Days until death				
≤1week	293(22.4)	54(7.3)	239(41.9)	**<0.001**
1 week~1 month	259(19.8)	118(16.0)	141(24.7)	
1 month~3 month	254(19.4)	161(21.8)	93(16.3)	
3 month~6 month	192(14.7)	141(19.1)	51(9.0)	
>6 month	310(23.7)	264(35.8)	46(8.1)	
End mode of the first episode				
Death	764(58.4)	370(50.2)	394(69.1)	**<0.001**
Others	528(40.4)	353(47.8)	175(30.7)	
Missing	16(1.2)	15(2.0)	1(0.2)	
Place of death				
Home	283(21.6)	283(38.3)	0(0.0)	**<0.001**
Residential Aged Care Facility	76(5.8)	76(10.3)	0(0.0)	

Hospital	282(21.6)	0(0.0)	282(49.5)	
Unknown	667(51.0)	379(51.4)	288(50.5)	

Abbreviations: N/A: Not applicable.

NOTE. Bold indicates significant value p < 0.05.

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

Episode of care characteristics

Compared to inpatients, the community group had a lower proportion of referrals from hospitals (29.1% vs. 44.4%), and a higher percentage of individuals living in private residences before the episode of care (83.5% vs. 73.5%, *p*<0.001). Community episodes most commonly commenced with a "stable" (41.1%) or "deteriorating" phase (53.5%), whereas inpatient episodes most frequently started with an "unstable" phase (40.2%) or "deteriorating" phase (33.9%) (*p*<0.001). The community group had a greater time between palliative care admission and death compared to the patients in the hospital (249 days vs. 31 days) (*p*<0.001). Half (49.1%) of inpatients survived less than 1 week, while the majority of people with MND (35.8%) in community palliative care services survived more than 6 months (*p*<0.001).

Comparisons of standard clinical measures between the two groups

Table 2 indicates that RUG-ADL scores of people with MND in CPC were significantly lower than those of inpatients (11.28 vs. 15.66, *p* < 0.001), and the AKPS score was significantly higher (46.08 vs. 32.27, *p* < 0.001). As indicated in the PCOC SAS scores, the two highest levels of distress were reported in relation to fatigue and breathing in both groups. Nausea within PCOC SAS scores of community palliative care individuals were lower than those of inpatient palliative care individuals (0.29 vs. 0.51, *p* = 0.042), as were scores related to breathing (2.56 vs. 3.13, *p* = 0.035) and pain (1.46 vs. 1.71, *p* < 0.001). Insomnia scores were higher than the inpatient group (1.58 vs. 1.54, *p* = 0.008) but fatigue scores were not significantly different across groups (3.29 vs. 2.97, *p* = 0.022). Nausea was the least prevalent symptom in both groups. For the scores on the PCPSS assessment, the pain domain was rated the lowest, and the other symptoms the highest. There were no statistical differences between the two groups except for the scores on the "other symptoms" category.

Table 2 Clinical outcome measures for patients with MND by episode settings

Clinical outcomes	N (patients)	All mean (SD) median (IQR)	Community mean (SD) median (IQR)	Hospital mean (SD) median (IQR)	p -values for differences by settings ⁎
AKPS	1270	40.11(16.82) 40(20,50)	46.08(0,62) 50(40,50)	32.27(0.69) 30(20,50)	**<0.001**
RUG-ADL					
Total RUG-ADL	1270	13.25(5.13) 15(10,18)	11.28(0.21) 12(6,16)	15.66(0.17) 18(14,18)	**<0.001**
Transfer	1279	3.70(1.53) 4(3,5)	3.13(0.06) 3(1,5)	4.39(0.05) 5(4,5)	**<0.001**
Mobility	1284	3.56(1.59) 4(3,5)	2.94(0.07) 3(1,5)	4.29(0.05) 5(4,5)	**<0.001**
Toileting	1282	3.67(1.53) 4(3,5)	3.08(0.07) 3(1,5)	4.36(0.05) 5(4,5)	**<0.001**
Eating	1271	2.34(0.81) 3(2,3)	2.13(0.03) 2(1,3)	2.62(0.03) 3(2,3)	**<0.001**
PCPSS					
Pain	1278	0.65(0.73) 1(0,1)	0.61(0.03) 1(0,1)	0.70(0.04) 0(0,1)	0.638
Other symptoms	1242	1.36(0.80) 1(1,2)	1.31(0.03) 1(1,2)	1.38(0.04) 1(1,2)	**0.015**

Psychological	1277	1.07(0.81) 1(1,2)	1.08(0.03) 1(1,1)	1.01(0.04) 1(0,2)	0.234
Family	1262	1.220.81) 1(1,2)	1.20(0.03) 1(1,2)	1.23(0.04) 1(1,2)	1.000
PCOC SAS					
Difficulty sleeping	1204	1.57(2.34) 0(0,3)	1.58(0.09) 0(0,3)	1.54(0.12) 0(0,3)	**0.008**
Appetite problems	1225	1.54(2.31) 0(0,3)	1.44(0.09) 0(0,2)	1.53(0.11) 0(0,3)	0.453
Nausea	1237	0.39(1.32) 0(0,0)	0.29(0.05) 0(0,0)	0.51(0.07) 0(0,0)	**0.042**
Bowels problems	1224	1.48(2.16) 0(0,2)	1.30(0.08) 0(0,2)	1.58(0.11) 0(0,3)	0.671
Breathing problems	1239	2.81(2.84) 2(0,5)	2.56(0.10) 2(0,4)	3.13(0.15) 2(0,5)	**0.035**
Fatigue	1233	3.22(2.75) 3(0,5)	3.29(0.10) 3(1,5)	2.97(0.14) 2(0,5)	**0.022**
Pain	1240	1.58(2.14) 1(0,2)	1.46(0.08) 1(0,2)	1.71(0.11) 0(0,3)	**<0.001**

Abbreviations: SD: Standard deviation, IQR: interquartile range, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, PCOC SAS: Symptom Assessment Scale.

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

⁎ Comparisons between the two groups were conducted using Mann–Whitney U test.

Factors associated with utilization of different specialist palliative care services

The final regression model (shown in Table 3) had a high C-statistic of 0.89 and included the following variables: age groups, sex, admission year, referral source, episode start accommodation, days until death, phase type, SAS appetite, PCPSS-pain, PCPSS-other symptoms, PCPSS-family, and RUG-ADL Total.

In the adjusted model, lower odds for entry into inpatient care were observed for people with MND who were accommodated at residential aged care facilities versus private residences (OR = 0.22; 95% CI: 0.11-0.45, p < 0.001), and also for those who had longer survival times after palliative care admission (ORs ranged from 0.02 to 0.18, p < 0.001 for all) versus less than 1 week of survival. Compared to those in the “stable” phase, people with MND in an “unstable” phase had increased odds for utilization of inpatient services versus community services (OR = 15.95; 95% CI: 7.43-34.27, p < 0.001). Higher dependency (ORs ranged from 2.32 to 11.73, p < 0.05 for all estimates) also predicted higher odds for inpatient service utilization. For PCPSS, relative to “absent” as the reference category, individuals with “mild” level of pain problems had lower odds of receiving inpatient palliative care services (OR = 0.59; 95% CI: 0.37-0.93, p < 0.05); a similar trend was also noted for those with “mild” and “moderate/severe” levels of family concern (ORs ranged from 0.36 to 0.38; p < 0.05 for both).

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

	Inpatient vs community unadjusted OR (95%CI, p -value) [a]	Inpatient vs community adjusted OR (95%CI, p -value) [b]	P for trend
Characteristics of patients and episodes of care			
Age groups (Ref. <65 years)			
≥65 years	1.09(0.87-1.37; 0.47)	1.20(0.76-1.89; 0.44)	0.472
Sex (Ref. male)	1.21(0.97-1.51; **0.09**)	1.13(0.74-1.73; 0.56)	
Admission of year (Ref. 2013)			
2014	0.97(0.59-1.59; 0.89)	1.05(0.42-2.61; 0.91)	**0.050**
2015	0.87(0.54-1.39; 0.55)	0.43(0.17-1.10; 0.08)	

2016	0.85(0.54-1.33; 0.47)	0.36(0.15-0.86; **0.02**)	
2017	0.61(0.39-0.97; **0.04**)	0.34(0.14-0.85; **0.02**)	
2018	0.76(0.49-1.20; 0.24)	0.43(0.18-1.02; 0.06)	
2019	0.61(0.39-0.96; **0.03**)	0.40(0.17-0.96; **0.04**)	
2020	0.87(0.53-1.40; 0.56)	0.42(0.17-1.07; 0.07)	
Referral source (Ref. hospital)			
Community service	0.67(0.52-0.86; **0.001**)	1.31(0.83-2.05; 0.24)	
Others	0.13(0.07-0.24; **<0.001**)	0.33(0.09-1.24; 0.10)	
Episode start accommodation (Ref. private residence)			
Residential aged care	0.54(0.35-0.82; **0.004**)	0.22(0.11-0.45; **<0.001**)	
Other	0.94(0.47-1.85; 0.85)	1.27(0.35-4.65; 0.72)	
Days until death (Ref. ≤1week)			
1 week ~ 1 month	0.27(0.18-0.40; **<0.001**)	0.18(0.09-0.34; **<0.001**)	**<0.001**
1 month ~ 3 months	0.13(0.09-0.19; **<0.001**)	0.09(0.04-0.18; **<0.001**)	
3 month ~ 6 months	0.08(0.05-0.13; **<0.001**)	0.08(0.04-0.16; **<0.001**)	
＞6 months	0.04(0.03-0.06; **<0.001**)	0.02(0.01-0.04; **<0.001**)	
Clinical measures			
Phase type (Ref. stable)			
Unstable	29.65(18.55-47.39; **<0.001**)	15.95(7.43-34.27; **<0.001**)	
Deteriorating	1.65(1.23-2.20; **0.001**)	0.65(0.38-1.11; 0.11)	
Terminal	13.95(7.43-26.17; **<0.001**)	0.66(0.22-1.96; 0.46)	
SAS appetite (Ref. absent)			
Mild	0.53(0.39-0.70; **<0.001**)	0.85(0.50-1.44; 0.54)	0.983
Moderate/severe	1.28(0.94-1.74; 0.12)	1.74(0.97-3.15; 0.07)	
PCPSS-pain (Ref. absent)			
Mild	0.72(0.56-0.91; **0.007**)	0.59(0.37-0.93; **0.03**)	0.258
Moderate/severe	1.69(1.19-2.40; **0.003**)	0.80(0.40-1.60; 0.53)	
PCPSS-family (Ref. absent)			
Mild	0.44(0.32-0.59; **<0.001**)	0.36(0.20-0.65; **0.001**)	0.290
Moderate/severe	0.69(0.50-0.96; **0.03**)	0.38(0.20-0.72; **0.003**)	
PCPSS-other symptoms (Ref. absent)			
Mild	0.48(0.33-0.68; **<0.001**)	1.06(0.54-2.10; 0.86)	0.550
Moderate/severe	0.78(0.55-1.12; 0.18)	0.62(0.30-1.27; 0.19)	
RUG-ADL Total (Ref. independent)			
Limited physical assistance	2.79(1.72-4.52; **<0.001**)	2.32(1.01-5.32; **0.05**)	**<0.001**
Requires one assistant plus equipment	5.35(3.31-8.63; **<0.001**)	3.67(1.56-8.65; **0.003**)	
Requires two assistants for full care	16.82(10.57-26.78; **<0.001**)	11.73(4.98-27.62; **<0.001**)	

Abbreviations: OR: odds ratios, CI: confidence interval, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, Ref.: reference.

[an] Unadjusted and adjusted OR values estimated based on univariate and multivariate binary logistic regression models. Patients admitted to community palliative care were used as the reference group.

[b] Adjusted models include all variables selected through stepwise procedures; unadjusted models include each specific variable.

OR values are calculated based on transformed categorical variables. Reference category for RUG-ADL Total: requires less than two assistants; for AKPS: not completely bedfast; for PCPSS and PCOC SAS: Absent.

Bold indicates significant value $p < 0.05$.

Discussion

This study assessed the palliative care needs and other clinical characteristics of individuals accessing palliative care principally for MND, and also explored how their clinical characteristics and care needs affected their use of community versus inpatient specialist palliative care. Overall, the majority of people with MND had low levels of symptom distress identified using the PCOC SAS, but relatively high levels of functional impairment. Disparities in symptom distress and severity between the groups were not consistently associated with the utilization of inpatient palliative care versus community palliative care, whereas individuals with higher dependence were more likely to access inpatient versus community care. Patterns of use of the different types of palliative care services were also highly associated with the palliative care phase and variables such as accommodation type and days until death.

In our study, symptom scores for both groups were mostly categorized as “absent” or “mild” only (supplementary material figures S1–S2). The data examined indicated higher levels of distress (ranging from moderate to severe) from fatigue and breathing problems relative to other symptoms. Previous studies of people with MND have reported that both of these symptoms are prevalent and often incapacitating [26,27]. Fatigue, which manifests as reversible motor weakness and feelings of intense fatigue throughout the entire body, is only partially alleviated by rest[28]. Moreover, respiratory failure is often the primary cause of death in many people with MND[29], and our study (similar to other studies) highlight the importance of implementing interventions that can help improve symptom control related to respiratory insufficiency and fatigue.

We also found that the level of symptom distress experienced by people with MND was not associated with their use of specialist palliative care settings. For example, there was a lower proportion of those diagnosed with MND admitted to inpatient palliative care services based on the severity of their symptoms. These findings are consistent with previous studies on lung cancer patients conducted by our team[15]. Although previous studies have generally reported better symptom outcomes for patients receiving inpatient versus community services[30–32], it is important to clarify whether inpatient care offers particular advantages in symptom management for the majority of people with MND in their final stage of life.

The observed associations between increased use of inpatient palliative care and lower levels of family concerns and pain are unexpected. This is most likely attributable to the closer contact between families and community providers[15], making community-based care providers typically have a greater awareness of "family concerns" and enabling them to better identify and address family/care-related distress[33]. In addition, the burden of hands-on care on family caregivers is substantial at home, especially when individuals are physically disabled and when their condition is deteriorating[34–36]. Given that the assessments of people included in the study were carried out upon their first admission to palliative care services, the patient’s family may - as a result of the patient’s entry to inpatient care - experience a reduction in distress and a partial relief from the burden of caring. The underlying reasons for the unexpected association between inpatient care and lower levels of pain need further exploration, while also noting that the nature and intensity of pain is highly variable with MND and its complications.

This study emphasized the contrasts in function and performance between the two groups of people with MND. The majority of people admitted to inpatient care required substantial assistance with daily living tasks (with mean RUG-ADL total scores >13), whereas those admitted to community care typically needed limited assistance, apart from in relation to the domain of eating (supplementary material figure S3). The AKPS results suggest that around 39% of individuals receiving community care experienced a gradual impairment in mobility, compared to 74% of inpatients (supplementary material figure S4). Additionally, it was also found that on average, inpatients had a much shorter time interval between palliative care admission and the occurrence of death compared to the individuals in the community care group (31 vs. 249 days). These findings suggest that the functional status at initiation of palliative care is a significant prognostic predictor in patients with MND, which aligns with previous studies on patients with cancer and dementia [15,37–39].

Our adjusted analyses revealed that individuals with high levels of dependency were more likely to utilize inpatient services compared to community-based services. Family caregivers [40] often face considerable challenges in caring for people with MND at home, especially when the individuals deteriorate or become clinically unstable[41]. Inpatient services, which provide highly specialized management 24 hours a day, can provide support for patients and their families in these circumstances[30]. Notably, nearly 74% of inpatients lived in private residences prior to admission, and 43% were referred from a community service. In terms of service delivery, these findings raise the possibility of providing greater levels of community-based support for families during this period, which may potentially allow some people to remain in home environment.

Given the incurable nature of MND and level of debility as an individual deteriorates, healthcare costs and hospital-based care tend to be significantly higher relative to other conditions[42]. Early access to palliative care services to maximize the quality of life for people with MND and their families has been recommended by several organizations[12,17]. In recent years, there has been a significant increase in access to specialist palliative care for non-cancer patients, including those with MND[43]. Notably, community-based services have been associated with improved end-of-life outcomes for people with non-cancer conditions, including reduced hospitalizations and decreased health system costs[43–45]. Although the average home care costs for the population receiving community-based palliative care are higher than those not receiving community-based palliative care, overall the reduced hospital expenses outweigh the increased home care costs [44]. Community-based care is typically encouraged for patients suffering from progressive, life-limiting disease in Australia[46], and has contributed to the rise in people with MND accessing such services. In this study, 56.4% (738) of people with MND received their first episode of palliative care services in a community setting.

Zwicker's study also found people with MND chose to receive community palliative care (through home care services and physician home visits) approximately twice as often as people without MND in the last year of life, suggesting that this is a population willing to utilize such services to address their complex healthcare needs[42]. Mobility of these individuals can often be impaired and there is significant difficulty with transporting individuals to hospital appointments. Access to specialist palliative care within the community environment would reduce this barrier[47]. Moreover, community-based care supports people in their familiar surroundings, enabling continuity of care by maintaining connections with their regular healthcare providers[30]. This approach is particularly beneficial for individuals with a strong family support system, as they are more likely to remain in the community[48]. However, at present the range of resources required for comprehensive care in the community setting is still limited[42,47]. In addition, there are gaps in the community-based specialist palliative care workforce [49], and generalist palliative care providers may not fully meet the distinctive needs of people with MND[26,50,51]. More investment in palliative care teams, medication access, care integration, and 24-hour home support services is required[15]. Furthermore, palliative care providers should also facilitate communication with patients and their families to clarify preferences and reduce unnecessary hospitalizations [41].

From January 1, 2013 to December 31, 2020, based on an average of 2 deaths from MND per day[4], approximately 5840 people may have died from MND. The number of MND deaths in the PCOC sample from this study accounts for 22.4% of the total deaths during these years. This indicates that this large-scale national study has reasonable representativeness in examining the clinical characteristics and care needs of Australian MND palliative care patients. Our study identified associations between the clinical characteristics and utilization of different types of specialist palliative care services among people with MND using standardized and validated assessment tools. These findings have implications for other countries with comparable systems of palliative care delivery. However, given that up to 50% of individuals with MND may have cognitive impairment[52], assessment results of many people with MND were likely to have been reported by proxies, such as family caregivers and health providers. Results reported in this study should therefore be interpreted with caution. Furthermore, it is important to note that the PCOC system may not capture information on particular patient characteristics and clinical needs that may influence their utilization of different types of palliative care services. For example, decisions about treatment interventions that affect the prognosis and survival of the patient (e.g. gastrostomy feeding, ventilatory support and use of drugs such as riluzole) may also affect the need for palliative care services but are not captured in detail by the PCOC system.

Conclusions

This study revealed that people with MND who had high levels of dependency and/or who were in an unstable clinical state were more likely to receive inpatient palliative care as opposed to community care. People residing in aged care facilities, as well as those with lower levels of symptom distress and/or family/carers distress, were more likely to receive community-based palliative care. Most people with MND in their last stage of life had high levels of physical impairment but relatively low symptom burdens as assessed with the clinical indicators used in this study. The degree of symptom distress was not significantly associated with patients' use of inpatient versus community-based palliative care. These findings suggest that more people with MND at the last stage of life could potentially benefit from increased access to supportive services in community settings, such as skilled palliative care providers and home support for family/carers. A need-based palliative care model for people with MND may assist with developing disease specific palliative care guidelines.

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References

1 Warrier MG, Thomas PT, Sadasivan A, *et al.* Development of Guidelines for Spouses Engaged in Home-Based Care of Persons With Motor Neuron Disease From Indian Context. *Journal of Patient Experience*. 2022;9:237437352210775.

2 National Institute for Health and Clinical Excellence (NICE). Motor neurone disease: assessment and management. 2016. nice.org.uk/guidance/ng42 (accessed 8 December 2022)

3 MND Australia. What is motor neurone disease? https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd (accessed 9 December 2022)

4 MND Australia. Motor Neurone Disease Information & Support | MND Australia. 2021. https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/overview-of-mnd-for-health-professionals (accessed 28 July 2023)

5 MND Association of South Africa. Motor Neurone Disease (MND). http://mnda.org.za/about-motor-neurone-disease-mnd/ (accessed 9 December 2022)

6 Clinical Standards Department at the Royal College of Physicians. Long-term Neurological Conditions: Management at the Interface Between Neurology,

Rehabilitation and Palliative Care. 2008. https://www.rcplondon.ac.uk/guidelines-policy/long-term-neurological-conditions (accessed 13 December 2022)

7 World Health Organization. Definition of Palliative Care. 2018. https://www.who.int/cancer/palliative/definition/en/ (accessed 2 March 2023)

8 Sutton L. Addressing palliative and end-of-life care needs in neurology. *British Journal of Neuroscience Nursing*. 2008;4:235–8.

9 Veronese S, Gallo G, Valle A, *et al.* Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study. *BMJ Support Palliat Care*. 2017;7:164–72.

10 Oliver DJ. Palliative care in motor neurone disease: where are we now? *Palliat Care*. 2019;12:1178224218813914.

11 Oliver DJ, Borasio GD, Caraceni A, *et al.* A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurol*. 2016;23:30–8.

12 National Institute for Health and Clinical Excellence (NICE). Motor neurone disease: assessment and management. 2016. https://www.nice.org.uk/guidance/ng42 (accessed 13 December 2022)

13 McNamara B, Rosenwax LK, Holman CDJ. A method for defining and estimating the palliative care population. *J Pain Symptom Manage*. 2006;32:5–12.

14 Nair K, Lee M, Hobson E, *et al.* End-of-life care of people with long-term neurological conditions. *PRACT NEUROL*. 2022;22:385–91.

15 Ding J, Johnson CE, Qin X, *et al.* Palliative care needs and utilisation of different specialist services in the last days of life for people with lung cancer. *Eur J Cancer Care*. 2021;30. doi: 10.1111/ecc.13331

16 Palliative Care Australia. Palliative Care Service Development Guidelines. 2018. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf (accessed 8 May 2023)

17 Oliver D, Borasio GD, Johnston W, editors. *Palliative care in amyotrophic lateral sclerosis: from diagnosis to bereavement*. Third edition. Oxford: Oxford University Press 2014.

18 Palliative Care Outcomes Collaboration. Palliative Care Outcomes Collaboration Clinical Manual. 2021. https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf (accessed 24 February 2023)

19 University of Wollongong. Palliative care outcomes collection. https://www.uow.edu.au/ahsri/pcoc/research-data/ (accessed 8 May 2023)

20 Aoun SM, Monterosso L, Kristjanson LJ, *et al.* Measuring Symptom Distress in Palliative Care: Psychometric Properties of the Symptom Assessment Scale (SAS). *Journal of Palliative Medicine*. 2011;14:315–21.

21 Masso M, Allingham SF, Johnson CE, *et al.* Palliative Care Problem Severity Score: Reliability and acceptability in a national study. *Palliat Med*. 2016;30:479–85.

22 Fries BE, Schneider DP, Foley WJ, *et al.* Refining a Case-Mix Measure for Nursing Homes: Resource Utilization Groups (RUG-III): *Medical Care*. 1994;32:668–85.

23 Abernethy AP, Shelby-James T, Fazekas BS, *et al.* The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliat Care*. 2005;4:7.

24 Masso M, Allingham SF, Banfield M, *et al.* Palliative Care Phase: Inter-rater reliability and acceptability in a national study. *Palliat Med*. 2015;29:22–30.

25 Australian Bureau of Statistics. SOCIO-ECONOMIC INDEXES FOR AREAS (SEIFA) 2016. 2023. https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~IRSAD~20 (accessed 27 April 2023)

26 Mc Veigh C, Donaghy C, Mc Laughlin B, *et al.* Palliative care for patients with motor neurone disease and their bereaved carers: a qualitative study. *BMC Palliat Care*. 2019;18:39.

27 Tiirola A, Korhonen T, Surakka T, *et al.* End-of-Life Care of Patients With Amyotrophic Lateral Sclerosis and Other Nonmalignant Diseases. *Am J Hosp Palliat Care*. 2017;34:154–9.

28 Gibbons CJ, Thornton EW, Young CA. The patient experience of fatigue in motor neurone disease. *Front Psychol*. 2013;4:788.

29 Miller RG, Jackson CE, Kasarskis EJ, *et al.* Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review). *Neurology*. 2009;73:1218–26.

30 Kamal AH, Currow DC, Ritchie CS, *et al.* Community-based palliative care: the natural evolution for palliative care delivery in the U.S. *J Pain Symptom Manage*. 2013;46:254–64.

31 Eagar K, Clapham SP, Allingham SF. Palliative care is effective: but hospital symptom outcomes superior. *BMJ Support Palliat Care*. 2020;10:186–90.

32 Clark K, Connolly A, Clapham S, *et al.* Physical Symptoms at the Time of Dying Was Diagnosed: A Consecutive Cohort Study To Describe the Prevalence and Intensity of Problems Experienced by Imminently Dying Palliative Care Patients by Diagnosis and Place of Care. *J Palliat Med*. 2016;19:1288–95.

33 de Graaf E, Zweers D, de Graeff A, *et al.* Symptom Intensity of Hospice Patients: A Longitudinal Analysis of Concordance Between Patients' and Nurses' Outcomes. *J Pain Symptom Manage*. 2018;55:272–81.

34 Aoun SM, Deas K, Kristjanson LJ, *et al.* Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool. *Palliat Support Care*. 2017;15:32–43.

35 Watermeyer TJ, Brown RG, Sidle KCL, *et al.* Impact of disease, cognitive and behavioural factors on caregiver outcome in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*. 2015;16:316–23.

36 Cheng HWB, Chan OMI, Chan CHR, *et al.* End-of-life Characteristics and Palliative Care Provision for Patients With Motor Neuron Disease. *Am J Hosp Palliat Care*. 2018;35:847–51.

37 Seow H, Barbera L, Sutradhar R, *et al.* Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. *J Clin Oncol*. 2011;29:1151–8.

38 Gwilliam B, Keeley V, Todd C, *et al.* Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ*. 2011;343:d4920.

39 Ding J, Cook A, Qin X, *et al.* 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.

40 Lerum SV, Solbraekke KN, Frich JC. Healthcare professionals' accounts of challenges in managing motor neurone disease in primary healthcare: a qualitative study. *Health Soc Care Community*. 2017;25:1355–63.

41 Warrier MG, Thomas PT, Sadasivan A, *et al.* Family Caregivers' Experiences with Dying and Bereavement of Individuals with Motor Neuron Disease in India. *J SOC WORK END-LIFE*. 2019;15:111–25.

42 Zwicker J, Qureshi D, Talarico R, *et al.* Dying of amyotrophic lateral sclerosis: Health care use and cost in the last year of life. *Neurology*. 2019;93:e2083–93.

43 Rosenwax L, Spilsbury K, McNamara BA, *et al.* A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? *BMC Palliat Care*. 2016;15:46.

44 Seow H, Salam-White L, Bainbridge D. Community-based specialist palliative care teams and health system costs at end of life: a retrospective matched cohort study. *CMAJ Open*. 2019;7:E73–80.

45 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 Palliat Care*. 2017;16:68.

46 Youens D, Moorin R. The Impact of 1on Utilization and Cost of Acute Care Hospital Services in the Last Year of Life. *Journal of Palliative Medicine*. 2017;20:736–44.

47 Olvera CE, Levin ME, Fleisher JE. Community-based neuropalliative care. *Handb Clin Neurol*. 2023;191:49–66.

48 Collis E, Al-Qurainy R. Care of the dying patient in the community. *BMJ*. 2013;347:f4085.

49 Australian Institute of Health and Welfare. Palliative care services in Australia, Palliative care workforce - Australian Institute of Health and Welfare. 2023. https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce (accessed 3 July 2023)

50 Brewah H, Borrett K, Tavares N, *et al.* Perceptions of people with motor neurone disease, families and HSCPs: a literature review. *Br J Community Nurs*. 2022;27:188–98.

51 Bentley B, O'Connor M. The End-of-Life Experiences of People with Motor Neuron Disease: Family Carers' Perspectives. *J PALLIAT MED*. 2016;19:857–62.

52 Miller RG, Jackson CE, Kasarskis EJ, *et al.* Practice Parameter update: The care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2009;73:1227–33.

Table 1 Baseline sociodemographic and clinical characteristics for people with MND by episode settings

Characteristics of Patients	**All N (%)**	**Community *N* (%)**	**Inpatient *N* (%)**	***p*-values for differences by setting**
Sociodemographic characteristics				
Total number	1308	738(56.4)	570(43.6)	-
Sex				
Male	712(54.4)	417(56.5)	295(51.8)	0.087
Female	596(45.6)	327(43.5)	275(48.2)	
Age				
< 65 years	457(34.9)	264(35.8)	193(33.9)	0.472
≥ 65 years	851(65.1)	474(64.2)	377(66.1)	
Preferred language				
English	1212(92.7)	682(92.4)	530(93.0)	0.695
Non-English	96(7.3)	56(7.6)	40(7.0)	
SEIFA				
1-2	183(14.0)	104(14.1)	79(13.9)	0.994
3-4	143(11.0)	79(10.7)	64(11.2)	
5-6	225(17.2)	128(17.4)	97(17.1)	
7-8	324(24.8)	181(24.5)	143(25.2)	
9-10	431(33.0)	246(33.3)	185(32.6)	
Characteristics of Episodes of Care				
Years of admission				
2013	127(9.7)	64(8.7)	63(11.1)	0.202
2014	121(9.3)	62(8.4)	59(10.3)	
2015	150(11.5)	81(11.0)	69(12.1)	
2016	187(14.3)	102(13.8)	85(14.9)	
2017	186(14.2)	116(15.7)	70(12.3)	
2018	198(15.1)	113(15.3)	85(14.9)	
2019	202(15.4)	126(17.1)	76(13.3)	
2020	137(10.5)	74(10.0)	63(11.1)	
Referral source				
Hospital	468(35.8)	215(29.1)	253(44.4)	**<0.001**
Community service	556(42.5)	311(42.1)	245(43.0)	
Others	86(6.6)	75(10.2)	11(1.9)	
Missing	198(15.1)	137(18.6)	61(10.7)	
Accommodation at the start of episode				
Private residence	1035(79.1)	616(83.5)	419(73.5)	**<0.001**
Residential aged care	116(8.9)	85(11.5)	31(5.4)	
Other	36(2.7)	22(3.0)	14(2.5)	
Missing	121(9.3)	15(2.0)	106(18.6)	
Phase type on admission				
Stable	393(30.0)	303(41.1)	90(15.8)	**<0.001**
Unstable	255(19.5)	26(3.5)	229(40.2)	
Deteriorating	588(45.0)	395(53.5)	193(33.8)	
Terminal	72(5.5)	14(1.9)	58(10.2)	
Days until death				
≤1week	293(22.4)	54(7.3)	239(41.9)	**<0.001**
1 week~1 month	259(19.8)	118(16.0)	141(24.7)	
1 month~3 month	254(19.4)	161(21.8)	93(16.3)	
3 month~6 month	192(14.7)	141(19.1)	51(9.0)	
>6 month	310(23.7)	264(35.8)	46(8.1)	
End mode of the first episode				
Death	764(58.4)	370(50.2)	394(69.1)	**<0.001**
Others	528(40.4)	353(47.8)	175(30.7)	

Missing	16(1.2)	15(2.0)	1(0.2)	
Place of death				
Home	283(21.6)	283(38.3)	0(0.0)	**<0.001**
Residential Aged Care Facility	76(5.8)	76(10.3)	0(0.0)	
Hospital	282(21.6)	0(0.0)	282(49.5)	
Unknown	667(51.0)	379(51.4)	288(50.5)	

Abbreviations: N/A: Not applicable.

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

* 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 outcome measures for patients with MND by episode settings

Clinical outcomes	N (patients)	All mean (SD) median (IQR)	Community mean (SD) median (IQR)	Hospital mean (SD) median (IQR)	p -values for differences by settings ∗
AKPS	1270	40.11(16.82) 40(20,50)	46.08(0,62) 50(40,50)	32.27(0.69) 30(20,50)	**<0.001**
RUG-ADL					
Total RUG-ADL	1270	13.25(5.13) 15(10,18)	11.28(0.21) 12(6,16)	15.66(0.17) 18(14,18)	**<0.001**
Transfer	1279	3.70(1.53) 4(3,5)	3.13(0.06) 3(1,5)	4.39(0.05) 5(4,5)	**<0.001**
Mobility	1284	3.56(1.59) 4(3,5)	2.94(0.07) 3(1,5)	4.29(0.05) 5(4,5)	**<0.001**
Toileting	1282	3.67(1.53) 4(3,5)	3.08(0.07) 3(1,5)	4.36(0.05) 5(4,5)	**<0.001**
Eating	1271	2.34(0.81) 3(2,3)	2.13(0.03) 2(1,3)	2.62(0.03) 3(2,3)	**<0.001**
PCPSS					
Pain	1278	0.65(0.73) 1(0,1)	0.61(0.03) 1(0,1)	0.70(0.04) 0(0,1)	0.638
Other symptoms	1242	1.36(0.80) 1(1,2)	1.31(0.03) 1(1,2)	1.38(0.04) 1(1,2)	**0.015**
Psychological	1277	1.07(0.81) 1(1,2)	1.08(0.03) 1(1,1)	1.01(0.04) 1(0,2)	0.234
Family	1262	1.220.81) 1(1,2)	1.20(0.03) 1(1,2)	1.23(0.04) 1(1,2)	1.000
PCOC SAS					
Difficulty sleeping	1204	1.57(2.34) 0(0,3)	1.58(0.09) 0(0,3)	1.54(0.12) 0(0,3)	**0.008**
Appetite problems	1225	1.54(2.31) 0(0,3)	1.44(0.09) 0(0,2)	1.53(0.11) 0(0,3)	0.453
Nausea	1237	0.39(1.32) 0(0,0)	0.29(0.05) 0(0,0)	0.51(0.07) 0(0,0)	**0.042**
Bowels problems	1224	1.48(2.16) 0(0,2)	1.30(0.08) 0(0,2)	1.58(0.11) 0(0,3)	0.671
Breathing problems	1239	2.81(2.84) 2(0,5)	2.56(0.10) 2(0,4)	3.13(0.15) 2(0,5)	**0.035**
Fatigue	1233	3.22(2.75) 3(0,5)	3.29(0.10) 3(1,5)	2.97(0.14) 2(0,5)	**0.022**
Pain	1240	1.58(2.14) 1(0,2)	1.46(0.08) 1(0,2)	1.71(0.11) 0(0,3)	**<0.001**

Abbreviations: SD: Standard deviation, IQR: interquartile range, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, PCOC SAS: Symptom Assessment Scale.

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

∗ Comparisons between the two groups were conducted using Mann–Whitney U test.

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

	Inpatient vs community unadjusted OR (95%CI, p -value) [a]	Inpatient vs community adjusted OR (95%CI, p -value) [b]	P for trend
Characteristics of patients and episodes of care			
Age groups (Ref. <65 years)			
≥65 years	1.09(0.87-1.37; 0.47)	1.20(0.76-1.89; 0.44)	0.472
Sex (Ref. male)	1.21(0.97-1.51; **0.09**)	1.13(0.74-1.73; 0.56)	
Admission of year (Ref. 2013)			
2014	0.97(0.59-1.59; 0.89)	1.05(0.42-2.61; 0.91)	**0.050**
2015	0.87(0.54-1.39; 0.55)	0.43(0.17-1.10; 0.08)	
2016	0.85(0.54-1.33; 0.47)	0.36(0.15-0.86; **0.02**)	
2017	0.61(0.39-0.97; **0.04**)	0.34(0.14-0.85; **0.02**)	
2018	0.76(0.49-1.20; 0.24)	0.43(0.18-1.02; 0.06)	
2019	0.61(0.39-0.96; **0.03**)	0.40(0.17-0.96; **0.04**)	
2020	0.87(0.53-1.40; 0.56)	0.42(0.17-1.07; 0.07)	
Referral source (Ref. hospital)			
Community service	0.67(0.52-0.86; **0.001**)	1.31(0.83-2.05; 0.24)	
Others	0.13(0.07-0.24; **<0.001**)	0.33(0.09-1.24; 0.10)	
Episode start accommodation (Ref. private residence)			
Residential aged care	0.54(0.35-0.82; **0.004**)	0.22(0.11-0.45; **<0.001**)	
Other	0.94(0.47-1.85; 0.85)	1.27(0.35-4.65; 0.72)	
Days until death (Ref. ≤1week)			
1 week ~ 1 month	0.27(0.18-0.40; **<0.001**)	0.18(0.09-0.34; **<0.001**)	**<0.001**
1 month ~ 3 months	0.13(0.09-0.19; **<0.001**)	0.09(0.04-0.18; **<0.001**)	
3 month ~ 6 months	0.08(0.05-0.13; **<0.001**)	0.08(0.04-0.16; **<0.001**)	
＞6 months	0.04(0.03-0.06; **<0.001**)	0.02(0.01-0.04; **<0.001**)	
Clinical measures			
Phase type (Ref. stable)			
Unstable	29.65(18.55-47.39; **<0.001**)	15.95(7.43-34.27; **<0.001**)	
Deteriorating	1.65(1.23-2.20; **0.001**)	0.65(0.38-1.11; 0.11)	
Terminal	13.95(7.43-26.17; **<0.001**)	0.66(0.22-1.96; 0.46)	
SAS appetite (Ref. absent)			
Mild	0.53(0.39-0.70; **<0.001**)	0.85(0.50-1.44; 0.54)	0.983
Moderate/severe	1.28(0.94-1.74; 0.12)	1.74(0.97-3.15; 0.07)	
PCPSS-pain (Ref. absent)			
Mild	0.72(0.56-0.91; **0.007**)	0.59(0.37-0.93; **0.03**)	0.258
Moderate/severe	1.69(1.19-2.40; **0.003**)	0.80(0.40-1.60; 0.53)	
PCPSS-family (Ref. absent)			
Mild	0.44(0.32-0.59; **<0.001**)	0.36(0.20-0.65; **0.001**)	0.290
Moderate/severe	0.69(0.50-0.96; **0.03**)	0.38(0.20-0.72; **0.003**)	
PCPSS-other symptoms (Ref. absent)			
Mild	0.48(0.33-0.68; **<0.001**)	1.06(0.54-2.10; 0.86)	0.550
Moderate/severe	0.78(0.55-1.12; 0.18)	0.62(0.30-1.27; 0.19)	
RUG-ADL Total (Ref. independent)			

Limited physical assistance	2.79(1.72-4.52; **<0.001**)	2.32(1.01-5.32; **0.05**)	**<0.001**
Requires one assistant plus equipment	5.35(3.31-8.63; **<0.001**)	3.67(1.56-8.65; **0.003**)	
Requires two assistants for full care	16.82(10.57-26.78; **<0.001**)	11.73(4.98-27.62; **<0.001**)	

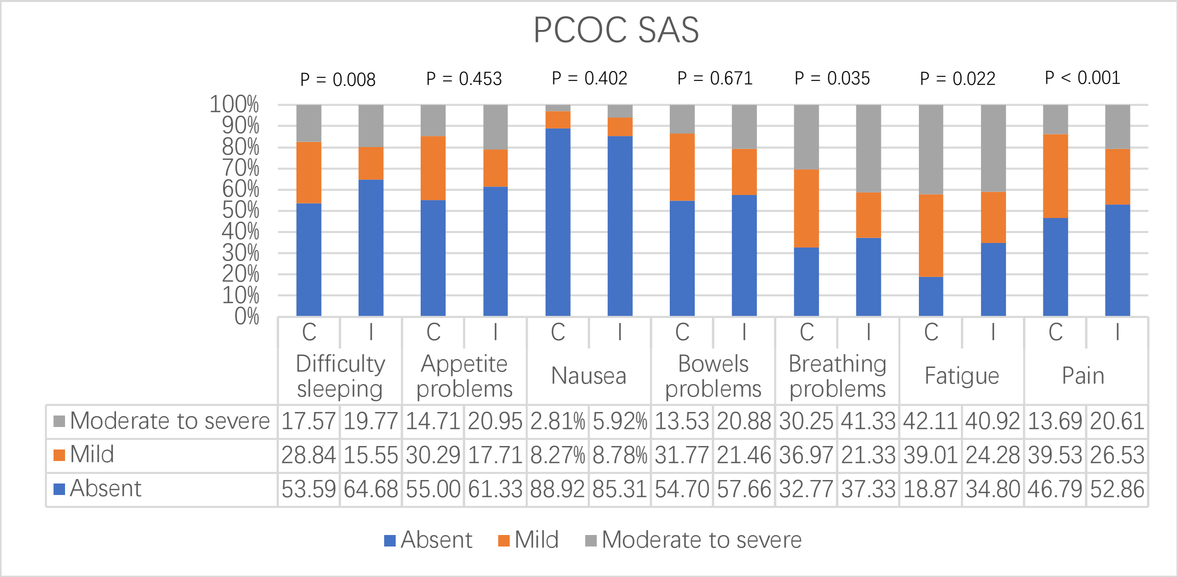
Abbreviations: OR: odds ratios, CI: confidence interval, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, Ref.: reference.

[an] Unadjusted and adjusted OR values estimated based on univariate and multivariate binary logistic regression models. Patients admitted to community palliative care were used as the reference group.

[b] Adjusted models include all variables selected through stepwise procedures; unadjusted models include each specific variable.

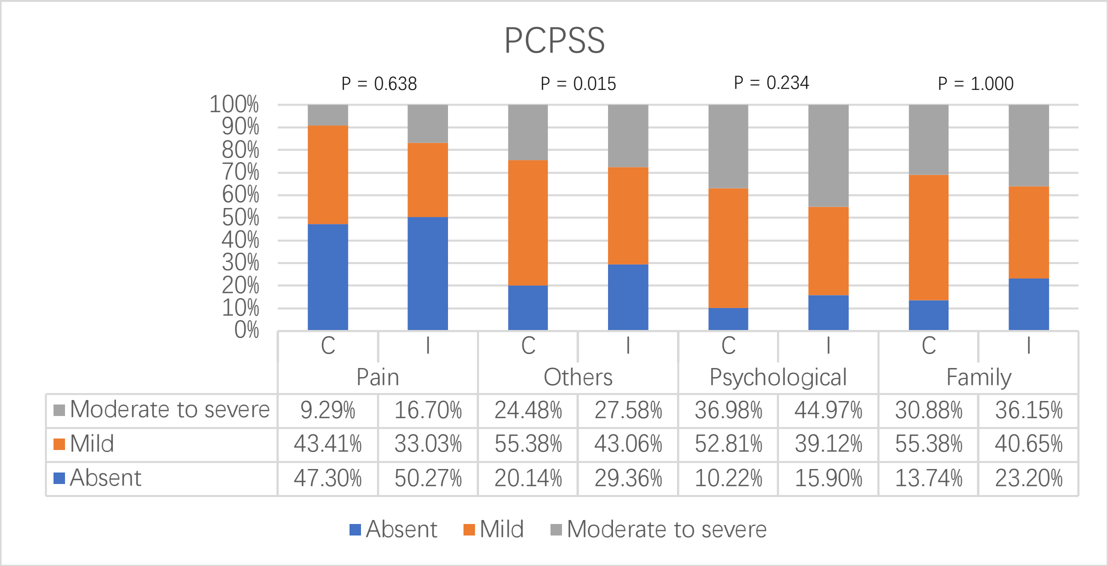
OR values are calculated based on transformed categorical variables. Reference category for RUG-ADL Total: requires less than two assistants; for AKPS: not completely bedfast; for PCPSS and PCOC SAS: Absent.

Bold indicates significant value $p < 0.05$.



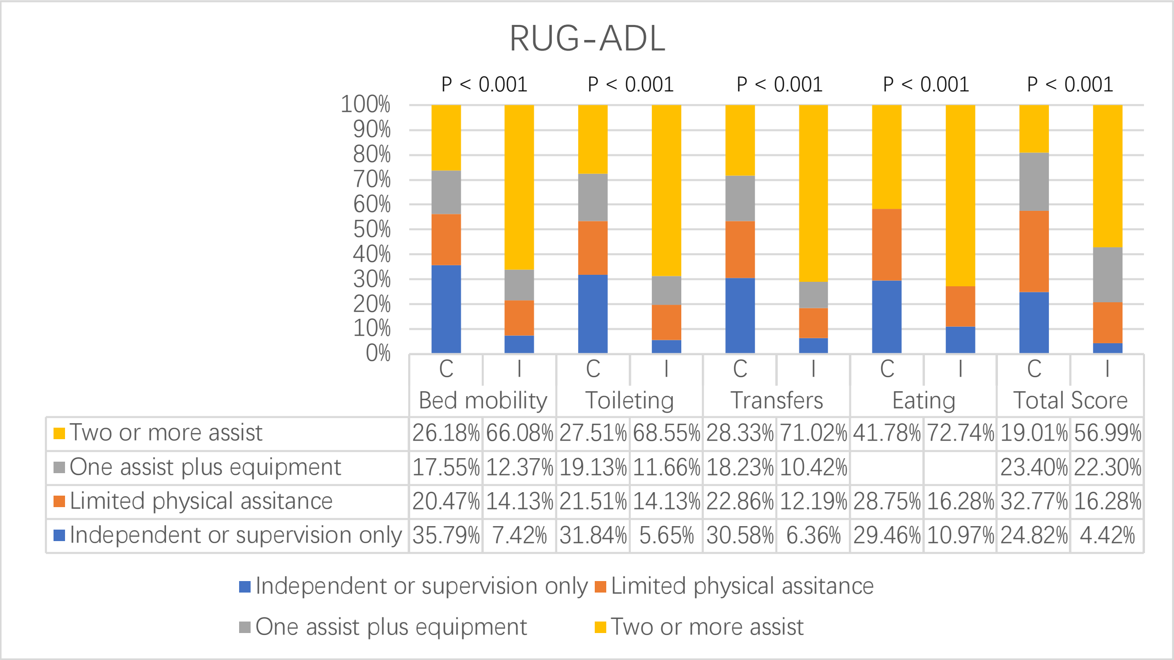
	Difficulty sleeping C	Difficulty sleeping I	Appetite problems C	Appetite problems I	Nausea C	Nausea I	Bowels problems C	Bowels problems I	Breathing problems C	Breathing problems I	Fatigue C	Fatigue I	Pain C	Pain I
■ Moderate to severe	17.57	19.77	14.71	20.95	2.81%	5.92%	13.53	20.88	30.25	41.33	42.11	40.92	13.69	20.61
■ Mild	28.84	15.55	30.29	17.71	8.27%	8.78%	31.77	21.46	36.97	21.33	39.01	24.28	39.53	26.53
■ Absent	53.59	64.68	55.00	61.33	88.92	85.31	54.70	57.66	32.77	37.33	18.87	34.80	46.79	52.86

Figure S1. *Distribution for levels of distress associated with patient-reported SAS symptoms*



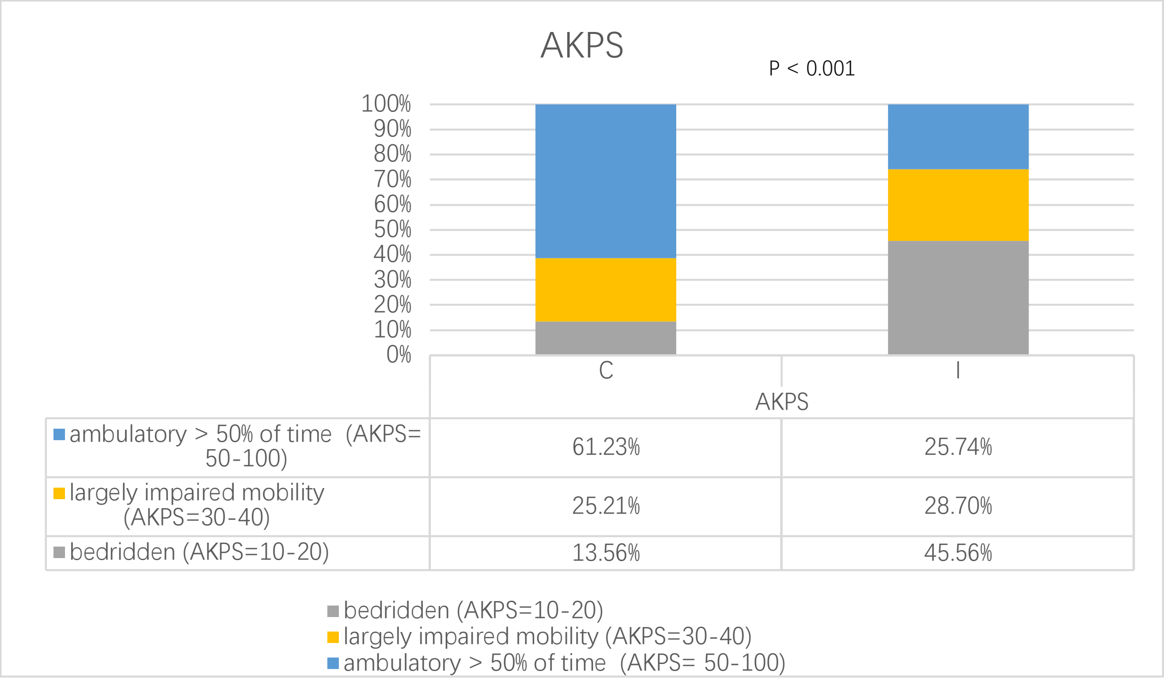
	Pain C	Pain I	Others C	Others I	Psychological C	Psychological I	Family C	Family I
■ Moderate to severe	9.29%	16.70%	24.48%	27.58%	36.98%	44.97%	30.88%	36.15%
■ Mild	43.41%	33.03%	55.38%	43.06%	52.81%	39.12%	55.38%	40.65%
■ Absent	47.30%	50.27%	20.14%	29.36%	10.22%	15.90%	13.74%	23.20%

Figure S2. *Distribution for levels of clinician-rated palliative care problems*



	Bed mobility C	Bed mobility I	Toileting C	Toileting I	Transfers C	Transfers I	Eating C	Eating I	Total Score C	Total Score I
Two or more assist	26.18%	66.08%	27.51%	68.55%	28.33%	71.02%	41.78%	72.74%	19.01%	56.99%
One assist plus equipment	17.55%	12.37%	19.13%	11.66%	18.23%	10.42%			23.40%	22.30%
Limited physical assitance	20.47%	14.13%	21.51%	14.13%	22.86%	12.19%	28.75%	16.28%	32.77%	16.28%
Independent or supervision only	35.79%	7.42%	31.84%	5.65%	30.58%	6.36%	29.46%	10.97%	24.82%	4.42%

Figure S3. *Distribution for levels of clinician-rated level of dependency*



	AKPS C	AKPS I
ambulatory > 50% of time (AKPS= 50-100)	61.23%	25.74%
largely impaired mobility (AKPS=30-40)	25.21%	28.70%
bedridden (AKPS=10-20)	13.56%	45.56%

Figure S4. *Distribution for levels of clinician-rated performance status*

For figures S1-4:

Abbreviations: C: Community patients; I: Inpatients

Comparisons of distributions between community patients and inpatients were performed using Pearson' s Chi-square test

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1,2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3,4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	12
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	Not applicable
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	5
		(*e*) Describe any sensitivity analyses	Not applicable
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6
		(b) Give reasons for non-participation at each stage	Not applicable
		(c) Consider use of a flow diagram	Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	6-8
		(b) Indicate number of participants with missing data for each variable of interest	6-8
Outcome data	15*	Report numbers of outcome events or summary measures	6-9
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8,9
		(*b*) Report category boundaries when continuous variables were categorized	6
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Not applicable
Discussion			
Key results	18	Summarise key results with reference to study objectives	10-12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12
Generalisability	21	Discuss the generalisability (external validity) of the study results	12
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	13

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Palliative care needs and utilization of specialist services for people diagnosed with motor neurone disease: A national population-based study

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TITLE PAGE

Title: Palliative care needs and utilization of specialist services for people diagnosed with motor neurone disease: A national population-based study

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Word count - Abstract: 276; Text: 6556
Figures:1; Tables: 3
Keywords: palliative care, motor neurone disease, Nursing Care, Health Services

Abstract

Introduction: There is a growing emphasis on the importance of the availability of specialist palliative care for people with motor neurone disease (MND). However, the palliative care needs and utilization of different specialist services of this population remain poorly defined.

Objectives: To (i) describe clinical characteristics, symptom burden and functional levels of patients dying with MND upon their admission to palliative care services; (ii) determine factors associated with receiving inpatient or community palliative care services.

Design: An observational study based on point-of-care data from the Australian Palliative Care Outcomes Collaboration (PCOC).

Participants: A total of 1,308 patients received palliative care principally because of MND between 1 January 2013 and 31 December 2020.

Measures: Five validated clinical instruments were used to assess each individual's function, distress from symptoms, symptom severity and urgency and acuity of their condition.

Results: Most MND patients had no or mild symptom distress, but experienced a high degree of functional impairment. Patients who were reported as requiring "two assistants for full care" relative to those who were "independent" (odds ratio = 11.53, 95% confidence interval: 4.87–27.26), and those in "unstable" relative to "stable" palliative care phases (odds ratio =16.74, 95% confidence interval: 7.73– 36.24), were more likely to use inpatient versus community-based palliative care. Associations between the use of different palliative care services and levels of symptom distress were not observed in this study.

Conclusions: More patients with MND primarily needed assistance for decreased function and activities of daily living, rather than symptom management. This population could have potentially been cared for in the palliative phase in a community setting if greater access to supportive services had been available in this context.

Keywords

palliative care, motor neurone disease, Nursing Care, Health Services

Strengths and limitations of this study

⇒ A major strength of this study lies in its large sample size, which was based on national population data.

⇒ In the palliative phase, people with motor neurone disease could potentially have been cared for in a community setting if greater access to supportive services had been available .

⇒ The data arising from this study spans a relatively long time period, including death cases that occurred from 2013 to 2020.

⇒ The limitation of this study is that the PCOC system (the data source of this study) may not fully capture information on particular patient characteristics and clinical needs that may influence their utilization of different types of palliative care services.

Introduction

Motor neurone disease (MND) is a neurodegenerative condition that progressively affects the brain and spinal cord, often leading to significant physical impairment and, in some cases, a locked-in state toward the end of life[1,2]. In Australia, it is estimated that approximately 2,100 individuals are living with MND[3] and on average, two people die each day from MND[4]. The average life expectancy varies and can range from two to five years or longer, depending on the severity and muscle groups affected by the disease[5]. As the illness progresses, many people living with MND experience a wide range of constantly changing care needs[1]. The UK's National Service Framework for Long-Term Conditions advocates life-long care for people diagnosed with long-term neurological conditions (LTNC) - including MND - and recommends an integrated approach involving neurology, rehabilitation, and palliative care to address the diagnostic, restorative, and palliative phases of illness[6].

Palliative care is generally defined as a multidisciplinary care approach to improve the quality of life for individuals facing life-limiting conditions and their families[7]. In recent years, there has been a growing recognition of the need for palliative care to be made available to all patients nearing the end of life, irrespective of their diagnosis, including those affected by MND[8]. Extensive research has shown the value of palliative care for people diagnosed with MND in alleviating clinical symptoms such as pain, dyspnea, sleep disturbances, and bowel symptoms, as well as improving the quality of life for both patients and their families[9–12]. However, non-malignant diseases such as MND are still under-represented in palliative care[13]. Although various palliative care strategies have been formulated, their applicability to people with MND is limited due to the unique palliative care requirements and disease trajectory [14]. Therefore, there is a need to optimize palliative care for people with MND by providing the 'right care in the right place at the right time'.

Palliative care in Australia is recognized internationally for its quality and accessibility[15]. Community-based palliative care (CPC) and inpatient palliative care (IPC) services are two essential settings of care that have different processes and structures, and resourcing and both are critical in providing palliative care. People living with a life-limiting illness should be able to access palliative care in different settings, depending on the complexity of their needs and preferences. Australian data indicate that 50% of people die in hospitals (which includes people in inpatient palliative care units), while the remaining 50% of people die in community settings. Some people's preferences for setting of care and death change after they are diagnosed with a life-limiting illness, as their illness progresses, or if their circumstances change[16]. Compared to inpatient options, community-based palliative care significantly improves symptom management and quality of life, while reducing healthcare utilization and costs for people at the end of life [17]. Community-based management can provide longitudinal support to patients and their families in different settings, making care more affordable and accessible [18]. However, people with complex and acute care needs may often require and should have ready access to inpatient palliative care.

There is increasing awareness of the role of palliative care for people diagnosed with neurological disorders[11], specifically for those with MND[10,12,19]. However, little evidence on the factors related to the utilization of different specialist services during the last few days of life has been reported. Such knowledge would enable the evaluation of whether individuals dying with MND receive the 'right care in the right place' and would also enhance care, and inform policy development, resource allocation, and personnel training. This study aimed to (a) describe the symptom burden and level of function of people with MND on their first admission to IPC and CPC before death, and (b) determine factors associated with receiving inpatient or community palliative care services.

Methods

Study design and data sources

De-identified, point-of-care data were collected by the Australian Palliative Care Outcomes Collaboration (PCOC) [20], a voluntary national program focused on improving the quality and outcomes in palliative care. The PCOC program, which is funded by the Australian Government Department of Health and Aged Care, evaluates patients in inpatient and community settings across various models of care. Any service in Australia that provides palliative care can participate in PCOC. The number of deaths reported in PCOC increased each year both in absolute terms and as a percentage of patients who might potentially benefit from palliative care (14.8% to 25.1%). In 2012, the national initiative reported 16,358 deaths, which increased to 32,421 deaths in 2022[21]. And now it comprises data describing more than 250,000 patients or residents [22]. Its dataset collects demographic, setting, and clinical assessment information for palliative care patients. Inpatient palliative care services conduct detailed assessments of individual patients upon admission and then at least daily and at phase change. Community palliative care services perform assessments on admission and during each subsequent encounter (e.g. each visit), in-person or by telephone/telehealth [22]. Data related to admission, phase changes, and discharge are reported to PCOC biannually. Before data are analyzed, the PCOC program conducts a review and data cleaning process. Participating services receive six-monthly reports on their performance which allows comparisons with national results and performance benchmarks established against industry standards.

Patient and public involvement

There was no direct patient or public involvement in this study.

Population and setting

This study included patients who met the following criteria: (i) required specialist palliative care from one or more of the services across Australia registered in PCOC; (ii) required palliative care principally for MND; (iii) with a first episode of care occurring between 1 January 2013 and 31 December 2020; and (iv) death occurring between 1 January 2013 and 31 December 2020. Two types of specialist palliative care episodes were included in this study: community and inpatient (including consult liaison services). An ‘inpatient episode’ refers to patients who have been seen in designated specialist palliative care units as well as in non-palliative care designated beds by specialist palliative care consultants/teams. A ‘community episode’ refers to people who receive specialist palliative care at private residences or residential care facilities[20]. The term ‘episode of care’ is defined as a continuous period of care for a patient in one setting, and an episode of care ends when the setting of care changes.

Variables and instruments

Five validated clinical instruments were used to assess clinical outcomes[20]. Levels of distress from symptoms (i.e. difficulties with sleeping, appetite, nausea, bowel symptoms, breathing problems, fatigue, and pain) were assessed using the 11-point Symptoms Assessment Scale (PCOC SAS) (0 – absent; 10 – worst possible)[23]. The PCOC SAS is ideally rated by the patient, but rating by proxies (i.e. family or clinicians) is permitted if the patient loses the capacity of self-assessment. The severity of patients' palliative care problems (pain, other symptoms, psychological/spiritual, and family/career concerns) were evaluated using the clinician-rated, four-point Palliative Care Problem Severity Score (PCPSS) (0–absent; 3–severe)[24]. Patients' level of functional dependency (eating, toileting, bed mobility, and transfers) were rated using the Resource Utilisation Groups - Activities of Daily Living (RUG-ADL), which scores eating based on a three-point item (1–independent or supervision only; 3–total dependence/tube fed), and the other three activities (toileting, bed mobility, and transfers) with five-point items (1–independent; 5–two or more persons assist)[25]. Performance status was determined by the 11-point Australia-modified Karnofsky Performance Status (AKPS) (0–dead; 100–complete function)[26]. The non-sequential Palliative Care Phase (Stable, Unstable, Deteriorating, or Terminal) is a holistic assessment of patients and their carers (including families) palliative needs and concerns[27]. The latter four of the tools were designed to be rated by trained clinicians.

Other clinical and socio-demographic characteristics involved in the study included sex, age, preferred language, years of admission, length of palliative care stay, referral source, accommodation at the start of the episode, and place of death. A summary measure of social and economic conditions, the Socio-Economic Indexes for Areas (SEIFA) [28], was also included. This indicator, developed by the Australian Bureau of Statistics, ranks areas in Australia according to relative socio-economic advantage and disadvantage, with scores ranging from 1 (very high levels of disadvantage) to 10 (very low levels of disadvantage).

This study focused on the first assessment conducted on admission to the inpatient or community care setting that is during the first episode of care for each patient. The variable 'end mode of the first episode' refers to the reason why the first episode of palliative care came to an end and 'death' is one of the categories within this variable.

Data analysis

Characteristics of participants and episodes were described using frequency and percentages. Standard clinical measures (RUG-ADL, AKPS, PCPSS, and SAS) were presented using means (standard deviation, SD) and medians (with interquartile range, IQR). Differences between the two types of specialist palliative care episodes (community and inpatient) were assessed using Pearson's chi-square tests (characteristics of participants and episodes) and Mann–Whitney U tests (length of stay and standard clinical measures)

Multivariable logistic regression analyses were conducted to identify factors associated with receiving inpatient or outpatient palliative care services. The multicollinearity of the model was assessed using variance inflation factors (VIF). Significant associated factors of different specialist services utilization were determined by using stepwise procedures. In our multivariate models, inclusion and exclusion criteria were set at significance levels of 0.05 and 0.10, respectively. We also utilized C-index to assess the fitness of the final model. Due to the high level of correlation within elements of the RUG-ADL family, we only selected "Total RUG-ADL" for the stepwise procedures. *P*-values for the trend of the following variables were calculated: age, days until death, and scores of symptoms and function. Patients receiving community services were used as the reference group.

In the regression analyses, PCOC SAS, PCPSS, total RUG-ADL, and AKPS were coded as categorical variables based on different clinical levels as follows: (i) Scores on PCOC SAS were classified as: 0 = absent (corresponding to PCOC SAS = 0), 1 = mild (PCOC SAS = 1–3), 2 = moderate to severe (PCOC SAS = 4–10); (ii) PCPSS was classified as follows: for PCPSS: 0 = absent (corresponding to PCPSS = 0), 1 = mild (PCPSS = 1), 2 = moderate to severe (PCPSS = 2–3); (iii) for AKPS: 1 = ambulatory > 50% of the time (corresponding to AKPS = 50–100), 2 = largely impaired mobility (AKPS = 30–40), 3 = bedridden (AKPS = 10–20). (iv) for RUG-ADL: 1 = independent (corresponding to total RUG-ADL = 4–5), 2 = limited physical assistance (total RUG-ADL = 6–13), 3 = requires one assistant plus equipment (total RUG-ADL = 14–17), 4 = requires two assistants for full care (total RUG-ADL = 18).

We fitted Kaplan-Meier curves and performed log-rank tests to compare survival time after admission between the two groups. Survival time was defined as the time interval between the date of first admission to a palliative care service to the date of death with a censor date of 31 December 2020.

Descriptive statistic estimation, logistic regression analyses, and collinearity analysis were performed using SPSS 26.0. The C-index and Kaplan-Meier curves were estimated using R statistical software version 4.0. *P*-values < 0.05 were considered statistically significant.

Results

Study population

A total of 1,308 people with MND were included in this study with 56.4% (738) accessing palliative care in a community setting and 43.6% (570) in an inpatient setting. A total of 54.4% were male, 34.9% were <65 years of age and 92.7% were from English-speaking families. More than 50% lived in areas with SEIFA category > 6. There were no statistically significant differences between the two groups for these sociodemographic characteristics. The specific sociodemographic and clinical characteristics for people with MND are shown in Table 1.

Table 1 Baseline sociodemographic and clinical characteristics for people with MND by episode settings

Characteristics of Patients	**All N (%)**	**Community *N* (%)**	**Inpatient *N* (%)**	***p*-values for differences by setting**
Sociodemographic characteristics				
Total number	1308	738(56.4)	570(43.6)	-
Sex				
Male	712(54.4)	417(56.5)	295(51.8)	0.087
Female	596(45.6)	327(43.5)	275(48.2)	
Age				
< 65 years	457(34.9)	264(35.8)	193(33.9)	0.660
65-75 years	474(36.2)	260(35.2)	214(37.5)	
> 75 years	377(28.8)	214(29.0)	163(28.6)	
Preferred language				
English	1212(92.7)	682(92.4)	530(93.0)	0.695
Non-English	96(7.3)	56(7.6)	40(7.0)	
SEIFA				
1-2	183(14.0)	104(14.1)	79(13.9)	0.994
3-4	143(11.0)	79(10.7)	64(11.2)	
5-6	225(17.2)	128(17.4)	97(17.1)	
7-8	324(24.8)	181(24.5)	143(25.2)	
9-10	431(33.0)	246(33.3)	185(32.6)	

Characteristics of Episodes of Care				
Years of admission				
2013	127(9.7)	64(8.7)	63(11.1)	0.202
2014	121(9.3)	62(8.4)	59(10.3)	
2015	150(11.5)	81(11.0)	69(12.1)	
2016	187(14.3)	102(13.8)	85(14.9)	
2017	186(14.2)	116(15.7)	70(12.3)	
2018	198(15.1)	113(15.3)	85(14.9)	
2019	202(15.4)	126(17.1)	76(13.3)	
2020	137(10.5)	74(10.0)	63(11.1)	
Referral source				
Hospital	468(35.8)	215(29.1)	253(44.4)	<0.001*
Community service	556(42.5)	311(42.1)	245(43.0)	
Others	86(6.6)	75(10.2)	11(1.9)	
Missing	198(15.1)	137(18.6)	61(10.7)	
Accommodation at the start of episode				
Private residence	1035(79.1)	616(83.5)	419(73.5)	<0.001*
Residential aged care	116(8.9)	85(11.5)	31(5.4)	
Other	36(2.7)	22(3.0)	14(2.5)	
Missing	121(9.3)	15(2.0)	106(18.6)	
Phase type on admission				
Stable	393(30.0)	303(41.1)	90(15.8)	<0.001*
Unstable	255(19.5)	26(3.5)	229(40.2)	
Deteriorating	588(45.0)	395(53.5)	193(33.8)	
Terminal	72(5.5)	14(1.9)	58(10.2)	
Days until death				
≤1week	293(22.4)	54(7.3)	239(41.9)	<0.001*
1 week~1 month	259(19.8)	118(16.0)	141(24.7)	
1 month~3 month	254(19.4)	161(21.8)	93(16.3)	
3 month~6 month	192(14.7)	141(19.1)	51(9.0)	
>6 month	310(23.7)	264(35.8)	46(8.1)	
The end mode of the first episode				
Death	764(58.4)	370(50.2)	394(69.1)	<0.001*
Others	528(40.4)	353(47.8)	175(30.7)	
Missing	16(1.2)	15(2.0)	1(0.2)	
Place of death				
Home	283(21.6)	283(38.3)	0(0.0)	<0.001*
Residential Aged Care Facility	76(5.8)	76(10.3)	0(0.0)	
Hospital	282(21.6)	0(0.0)	282(49.5)	
Unknown	667(51.0)	379(51.4)	288(50.5)	

Abbreviations: N/A: Not applicable.

NOTE. * indicates significant value p < 0.05.

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

Episode of care characteristics

On average, inpatients had a much shorter time interval between palliative care admission and death compared to the individuals in the community care group (31 days vs. 249 days; P < 0.0001) (Figure 1). Compared to inpatients, the community group had a lower proportion of referrals from hospitals (29.1% vs. 44.4%), and a higher percentage of individuals living in private residences before the episode of care (83.5% vs. 73.5%, *p*<0.001). Community episodes most commonly commenced with a “stable” (41.1%) or “deteriorating” phase (53.5%), whereas inpatient episodes most frequently started with an “unstable” phase (40.2%) or “deteriorating” phase (33.9%) (*p*<0.001). The community group had a greater time between palliative care admission and death compared to the patients in the hospital (249 days vs. 31 days) (*p*<0.001). Half (49.1%) of inpatients survived less than 1 week, while the majority of people with MND (35.8%) in community palliative care services survived more than 6 months (*p*<0.001).

Comparisons of standard clinical measures between the two groups

Table 2 indicates that RUG-ADL scores of people with MND in CPC were significantly lower than those of inpatients (11.28 vs. 15.66, *p* < 0.001), and the AKPS score was significantly higher (46.08 vs. 32.27, *p* < 0.001). As indicated in the PCOC SAS scores, the two highest levels of distress were reported concerning fatigue and breathing in both groups. Nausea within PCOC SAS scores of community palliative care individuals were lower than those of inpatient palliative care individuals (0.29 vs. 0.51, *p* = 0.042), as were scores related to breathing (2.56 vs. 3.13, *p* = 0.035) and pain (1.46 vs. 1.71, *p* < 0.001). Insomnia scores were higher than the inpatient group (1.58 vs. 1.54, *p* = 0.008) but fatigue scores were not significantly different across groups (3.29 vs. 2.97, *p* = 0.022). Nausea was the least prevalent symptom in both groups. For the scores on the PCPSS assessment, the pain domain was rated the lowest, and the other symptoms the highest. There were no statistical differences between the two groups except for the scores on the “other symptoms” category.

Table 2 Clinical outcome measures for patients with MND by episode settings

Clinical outcomes	N (patients)	All mean (SD) median (IQR)	Community mean (SD) median (IQR)	Hospital mean (SD) median (IQR)	p -values for differences by settings *
AKPS	1270	40.11(16.82) 40(20,50)	46.08(0,62) 50(40,50)	32.27(0.69) 30(20,50)	<0.001*
RUG-ADL					
Total RUG-ADL	1270	13.25(5.13) 15(10,18)	11.28(0.21) 12(6,16)	15.66(0.17) 18(14,18)	<0.001*
Transfer	1279	3.70(1.53) 4(3,5)	3.13(0.06) 3(1,5)	4.39(0.05) 5(4,5)	<0.001*
Mobility	1284	3.56(1.59) 4(3,5)	2.94(0.07) 3(1,5)	4.29(0.05) 5(4,5)	<0.001*
Toileting	1282	3.67(1.53) 4(3,5)	3.08(0.07) 3(1,5)	4.36(0.05) 5(4,5)	<0.001*
Eating	1271	2.34(0.81) 3(2,3)	2.13(0.03) 2(1,3)	2.62(0.03) 3(2,3)	<0.001*
PCPSS					
Pain	1278	0.65(0.73) 1(0,1)	0.61(0.03) 1(0,1)	0.70(0.04) 0(0,1)	0.638
Other symptoms	1242	1.36(0.80) 1(1,2)	1.31(0.03) 1(1,2)	1.38(0.04) 1(1,2)	0.015*
Psychological	1277	1.07(0.81) 1(1,2)	1.08(0.03) 1(1,1)	1.01(0.04) 1(0,2)	0.234
Family	1262	1.220.81) 1(1,2)	1.20(0.03) 1(1,2)	1.23(0.04) 1(1,2)	1.000
PCOC SAS					
Difficulty sleeping	1204	1.57(2.34) 0(0,3)	1.58(0.09) 0(0,3)	1.54(0.12) 0(0,3)	0.008*
Appetite problems	1225	1.54(2.31) 0(0,3)	1.44(0.09) 0(0,2)	1.53(0.11) 0(0,3)	0.453
Nausea	1237	0.39(1.32) 0(0,0)	0.29(0.05) 0(0,0)	0.51(0.07) 0(0,0)	0.042*
Bowels problems	1224	1.48(2.16) 0(0,2)	1.30(0.08) 0(0,2)	1.58(0.11) 0(0,3)	0.671
Breathing problems	1239	2.81(2.84) 2(0,5)	2.56(0.10) 2(0,4)	3.13(0.15) 2(0,5)	0.035*
Fatigue	1233	3.22(2.75) 3(0,5)	3.29(0.10) 3(1,5)	2.97(0.14) 2(0,5)	0.022*
Pain	1240	1.58(2.14) 1(0,2)	1.46(0.08) 1(0,2)	1.71(0.11) 0(0,3)	<0.001*

Abbreviations: SD: Standard deviation, IQR: interquartile range, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, PCOC SAS: Symptom Assessment Scale.
NOTE. * indicates significant value *p* < 0.05.
Comparisons between the two groups were conducted using the Mann–Whitney U test.

Factors associated with the utilization of different specialist palliative care services

The final regression model (shown in Table 3) had a high C-statistic of 0.89 and included the following variables: age groups, sex, admission year, referral source, episode start accommodation, days until death, phase type, SAS appetite, PCPSS-pain, PCPSS-other symptoms, PCPSS-family, and RUG-ADL Total.

In the adjusted model, lower odds for entry into inpatient care were observed for people with MND who were accommodated at residential aged care facilities versus private residences (OR = 0.24; 95% CI: 0.12-0.49, $p < 0.001$), and also for those who had longer survival times after palliative care admission (ORs ranged from 0.02 to 0.18, $p < 0.001$ for all) versus less than 1 week of survival. Compared to those in the “stable” phase, people with MND in an “unstable” phase had increased odds for utilization of inpatient services versus community services (OR = 16.74; 95% CI: 7.73-36.24, $p < 0.001$). Higher levels of dependency (ORs ranged from 3.56 to 11.33, $p < 0.05$ for all estimates) also predicted higher odds for inpatient service utilization. For PCPSS, relative to “absent” as the reference category, individuals with “mild” level of pain problems had lower odds of receiving inpatient palliative care services (OR = 0.58; 95% CI: 0.37-0.93, $p < 0.05$); a similar trend was also noted for those with “mild” and “moderate/severe” levels of family concern (ORs ranged from 0.35 to 0.36; $p < 0.05$ for both).

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

	Inpatient vs community unadjusted OR (95%CI, p-value [a]	Inpatient vs community adjusted OR (95%CI, p-value) [b]	P for trend
Characteristics of patients and episodes of care			
Age groups (Ref. <65 years)			
65-75 years	1.13(0.87-1.46; 0.37)	1.50(0.89-2.53; 0.13)	0.734
> 75 years	1.04(0.79-1.37;0.77)	0.90(0.52-1.56; 0.72)	
Sex (Ref. male)	1.21(0.97-1.51; 0.09*)	1.13(0.74-1.73; 0.59)	
Admission of year (Ref. 2013)			
2014	0.97(0.59-1.59; 0.89)	1.04(0.42-2.60; 0.93)	0.050*
2015	0.87(0.54-1.39; 0.55)	0.43(0.17-1.09; 0.08)	
2016	0.85(0.54-1.33; 0.47)	0.36(0.15-0.86; 0.02*)	
2017	0.61(0.39-0.97; 0.04*)	0.33(0.13-0.83; 0.02*)	
2018	0.76(0.49-1.20; 0.24)	0.41(0.17-0.97; 0.04*)	
2019	0.61(0.39-0.96; 0.03*)	0.38(0.16-0.93; 0.03*)	
2020	0.87(0.53-1.40; 0.56)	0.41(0.16-1.03; 0.06)	
Referral source (Ref. hospital)			
Community service	0.67(0.52-0.86; 0.001*)	1.32(0.84-2.07; 0.23)	
Others	0.13(0.07-0.24; <0.001*)	0.32(0.09-1.22; 0.10)	
Episode start accommodation (Ref. private residence)			
Residential aged care	0.54(0.35-0.82; 0.004*)	0.24(0.12-0.49; <0.001*)	
Other	0.94(0.47-1.85; 0.85)	1.32(0.35-4.95; 0.68)	
Days until death (Ref. ≤ 1 week)			
1 week ~ 1 month	0.27(0.18-0.40; <0.001*)	0.18(0.09-0.34; <0.001*)	<0.001 *
1 month ~ 3 months	0.13(0.09-0.19; <0.001*)	0.08(0.04-0.16; <0.001*)	
3 month ~ 6 months	0.08(0.05-0.13; <0.001*)	0.07(0.03-0.15; <0.001*)	
> 6 months	0.04(0.03-0.06; <0.001*)	0.02(0.01-0.04; <0.001*)	
Clinical measures			
Phase type (Ref. stable)			
Unstable	29.65(18.55-47.39; <0.001*)	16.74(7.73-36.24; <0.001*)	

Deteriorating	1.65(1.23-2.20; 0.001*)	0.68(0.40-1.15; 0.15)	
Terminal	13.95(7.43-26.17; <0.001*)	0.70(0.23-2.07; 0.52)	
SAS appetite (Ref. absent)			
Mild	0.53(0.39-0.70; <0.001*)	0.86(0.50-1.46; 0.57)	0.983
Moderate/severe	1.28(0.94-1.74; 0.12)	1.78(0.99-3.22; 0.06)	
PCPSS-pain (Ref. absent)			
Mild	0.72(0.56-0.91; 0.007*)	0.58(0.37-0.93; 0.03*)	0.258
Moderate/severe	1.69(1.19-2.40; 0.003*)	0.78(0.39-1.57; 0.49)	
PCPSS-family (Ref. absent)			
Mild	0.44(0.32-0.59; <0.001*)	0.36(0.20-0.64; 0.001*)	0.290
Moderate/severe	0.69(0.50-0.96; 0.03*)	0.35(0.18-0.67; 0.002*)	
PCPSS-other symptoms (Ref. absent)			
Mild	0.48(0.33-0.68; <0.001*)	1.07(0.54-2.12; 0.84)	0.550
Moderate/severe	0.78(0.55-1.12; 0.18)	0.60(0.29-1.24; 0.17)	
RUG-ADL Total (Ref. independent)			
Limited physical assistance	2.79(1.72-4.52; <0.001*)	2.23(0.98-5.19 0.06)	<0.001 *
Requires one assistant plus equipment	5.35(3.31-8.63; <0.001*)	3.65(1.54-8.65; 0.003*)	
Requires two assistants for full care	16.82(10.57-26.78; <0.001*)	11.53(4.87-27.26; <0.001*)	

Abbreviations: OR: odds ratios, CI: confidence interval, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, Ref.: reference.

[a] Unadjusted and adjusted OR values estimated based on univariate and multivariate binary logistic regression models. Patients admitted to community palliative care were used as the reference group.

[b] Adjusted models include all variables selected through stepwise procedures; unadjusted models include each specific variable.

OR values are calculated based on transformed categorical variables. Reference category for RUG-ADL Total: requires less than two assistants; for AKPS: not completely bedfast; for PCPSS and PCOC SAS: Absent.

* indicates significant value $p < 0.05$.

Discussion

This study assessed the palliative care needs and other clinical characteristics of individuals accessing palliative care principally for MND, and also explored factors associated with receiving inpatient or community palliative care services. Overall, the majority of people with MND had low levels of symptom distress identified using the PCOC SAS, but relatively high levels of functional impairment. Disparities in symptom distress and severity between the groups were not consistently associated with the utilization of inpatient palliative care versus community palliative care, whereas individuals with higher dependence were more likely to access inpatient versus community care. Patterns of use of the different types of palliative care services were also highly associated with the palliative care phase and variables such as accommodation type and days until death.

In our study, symptom scores for both groups were mostly categorized as “absent” or “mild” only (supplementary material figures S1–S2). The data examined indicated higher levels of distress (ranging from moderate to severe) from fatigue and breathing problems relative to other symptoms. Previous studies of people with MND have reported that both of these symptoms are prevalent and often incapacitating [29,30]. Fatigue, which manifests as reversible motor weakness and feelings of intense fatigue throughout the entire body, is only partially alleviated by rest[31]. Moreover, respiratory failure is often the primary cause of death in many people with MND[32], and our study (similar to other studies) highlights the importance of implementing interventions that can help improve symptom control related to respiratory insufficiency and fatigue.

We also found that the level of symptom distress experienced by people with MND was not associated with their use of specialist palliative care settings. For example, there was a lower proportion of those diagnosed with MND admitted to inpatient palliative care services based on the severity of their symptoms. These findings are consistent with previous studies on lung cancer patients conducted by our team[15]. Although previous studies have generally reported better symptom outcomes for patients receiving inpatient versus community services[33–35], it is important to clarify whether inpatient care offers particular advantages in symptom management for the majority of people with MND in their final stage of life.

The observed associations between increased use of inpatient palliative care and lower levels of family concerns and pain are unexpected. This is most likely attributable to the closer contact between families and community providers[15], making community-based care providers typically have a greater awareness of "family concerns" and enabling them to better identify and address family/care-related distress[36]. In addition, the burden of hands-on care on family caregivers is substantial at home, especially when individuals are physically disabled and when their condition is deteriorating[37–39]. Given that the assessments of people included in the study were carried out upon their first admission to palliative care services, the patient’s family may - as a result of the patient’s entry to inpatient care - experience a reduction in distress and partial relief from the burden of caring. The underlying reasons for the unexpected association between inpatient care and lower levels of pain need further exploration, while also noting that the nature and intensity of pain is highly variable with MND and its complications.

This study emphasized the contrasts in function and performance between the two groups of people with MND. The majority of people admitted to inpatient care required substantial assistance with daily living tasks (with mean RUG-ADL total scores >13), whereas those admitted to community care typically needed more limited assistance (supplementary material figure S3). The AKPS results suggest that around 39% of individuals receiving community care experienced a gradual impairment in mobility, compared to 74% of inpatients (supplementary material figure S4). Additionally, it was also found that inpatients had a much shorter time interval between palliative care admission and the occurrence of death compared to the individuals in the community care group (31 vs. 249 days). These findings suggest that the functional status at initiation of palliative care is a significant prognostic predictor in patients with MND, which aligns with previous studies on patients with cancer and dementia [15,40–42].

Our adjusted analyses revealed that individuals with high levels of dependency were more likely to utilize inpatient services compared to community-based services. Family caregivers [43] often face considerable challenges in caring for people with MND at home, especially when the individuals deteriorate or become clinically unstable[44]. Inpatient services, which provide highly specialized management 24 hours a day, can provide support for patients and their families in these circumstances[33]. Notably, nearly 74% of inpatients lived in private residences before admission, and 43% were referred to a community service. In terms of service delivery, these findings raise the possibility of providing greater levels of community-based support for families during this period, which may potentially allow some people to remain in the home environment.

Given the incurable nature of MND and the level of debility as an individual deteriorates, healthcare costs and hospital-based care tend to be significantly higher relative to other conditions [45]. Early access to palliative care services to maximize the quality of life for people with MND and their families has been recommended by several organizations [12,19]. In recent years, there has been a significant increase in access to specialist palliative care for non-cancer patients, including those with MND [46]. Notably, community-based services have been associated with improved end-of-life outcomes for people with non-cancer conditions, including reduced hospitalizations and decreased health system costs [46]. Although the average home care costs for the population receiving community-based palliative care are higher than those not receiving community-based palliative care, overall the reduced hospital expenses outweigh the increased home care costs [44]. Community-based care is typically encouraged for patients suffering from progressive, life-limiting disease in Australia [47], and has contributed to the rise in people with MND accessing such services. In this study, 56.4% (738) of people with MND received their first episode of palliative care services in a community setting.

Zwicker's study also found people with MND chose to receive community palliative care (through home care services and physician home visits) approximately twice as often as people without MND in the last year of life, suggesting that this is a population willing to utilize such services to address their complex healthcare needs [45]. Mobility of these individuals can often be impaired and there is significant difficulty with transporting individuals to hospital appointments. Access to specialist palliative care within the community environment would reduce this barrier[48]. Moreover, community-based care supports people in their familiar surroundings, enabling continuity of care by maintaining connections with their regular healthcare providers[33]. This approach is particularly beneficial for individuals with a strong family support system, as they are more likely to remain in the community[49]. However, at present the range of resources required for comprehensive care in the community setting is still limited[45,48]. In addition, there are gaps in the community-based specialist palliative care workforce [50], and generalist palliative care providers may not fully meet the distinctive needs of people with MND[29,51,52]. More investment in palliative care teams, medication access, care integration, and 24-hour home support services is required[15]. Furthermore, palliative care providers should also facilitate communication with patients and their families to clarify preferences and reduce unnecessary hospitalizations [44].

From January 1, 2013, to December 31, 2020, based on an average of 2 deaths from MND per day[4], approximately 5840 people may have died from MND. The number of MND deaths in the PCOC sample from this study accounts for 22.4% of the total deaths during these years. This indicates that this large-scale national study has reasonable representativeness in examining the clinical characteristics and care needs of Australian MND palliative care patients. Our study identified associations between the clinical characteristics and utilization of different types of specialist palliative care services among people with MND using standardized and validated assessment tools. These findings have implications for other countries with comparable systems of palliative care delivery.

Limitations

This study has several limitations. Given that up to 50% of individuals with MND may have cognitive impairment [53] and/or significant difficulties with communication, assessment results of many people with MND were likely to have been reported by proxies, such as family caregivers and health providers. Results reported in this study should therefore be interpreted with caution. Furthermore, it is important to note that the PCOC system may not capture information on particular patient characteristics and clinical needs that may influence their utilization of different types of palliative care services. For example, decisions about treatment interventions that affect the prognosis and survival of the patient (e.g. gastrostomy feeding, ventilatory support, and use of drugs such as riluzole) may also affect the need for palliative care services but are not captured in detail by the PCOC system. Finally, people with MND may have the limited access to palliative care, some were cared for in aged care homes (given the age >65 years of many people dying with MND) which had limited access to palliative care services during the study period.

Conclusions

This study revealed that people with MND who had high levels of dependency and/or who were in an unstable clinical state were more likely to receive inpatient palliative care as opposed to community care. People residing in aged care facilities, as well as those with lower levels of symptom distress and/or family/carers distress, were more likely to receive community-based palliative care. Most people with MND in their last stage of life had high levels of physical impairment but relatively low symptom burdens as assessed with the clinical indicators used in this study. The degree of symptom distress was not significantly associated with patients' use of inpatient versus community-based palliative care. These findings suggest that more people with MND at the last stage of life could potentially benefit from increased access to supportive services in community settings, such as skilled palliative care providers and home support for family/carers. A need-based palliative care model for people with MND may assist with developing disease-specific palliative care guidelines.

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Author Contributors: Conceptualization: WB. Methodology: WB, HL. Writing - Original Draft: WB. Formal analysis, Data Curation, statistical analysis, and Project administration: JD. Supervision: HZ. Writing - Review & Editing: HL, CEJ, AC. Validation and statistical review: CEJ, AC. All authors have read and approved the final version of the manuscript.

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Competing interests: The authors declare that they have no conflicts of interest.

Patient consent for publication: Not required.

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Data availability statement: The research findings presented in this study are underpinned by data sourced from the Palliative Care Outcomes Collaboration (PCOC) in Australia. Access to this data is subject to certain permissions from PCOC, as it is utilized under a specific license agreement for this study. For those interested in accessing the original data supporting this study, we encourage you to directly request access to the dataset from PCOC through the following link: https://www.uow.edu.au/ahsri/pcoc/research-data/.

References

1 Warrier MG, Thomas PT, Sadasivan A, *et al.* Development of Guidelines for Spouses Engaged in Home-Based Care of Persons With Motor Neuron Disease From Indian Context. *Journal of Patient Experience*. 2022;9:237437352210775.

2 National Institute for Health and Clinical Excellence (NICE). Motor neurone disease: assessment and management. 2016. nice.org.uk/guidance/ng42 (accessed 8 December 2022)

3 MND Australia. What is motor neurone disease? https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd (accessed 9 December 2022)

4 MND Australia. Motor Neurone Disease Information & Support | MND Australia. 2021. https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/overview-of-mnd-for-health-professionals (accessed 28 July 2023)

5 MND Association of South Africa. Motor Neurone Disease (MND). http://mnda.org.za/about-motor-neurone-disease-mnd/ (accessed 9 December 2022)

6 Clinical Standards Department at the Royal College of Physicians. Long-term Neurological Conditions: Management at the Interface Between Neurology, Rehabilitation and Palliative Care. 2008. https://www.rcplondon.ac.uk/guidelines-policy/long-term-neurological-conditions (accessed 13 December 2022)

7 World Health Organization. Definition of Palliative Care. 2018. https://www.who.int/cancer/palliative/definition/en/ (accessed 2 March 2023)

8 Sutton L. Addressing palliative and end-of-life care needs in neurology. *British Journal of Neuroscience Nursing*. 2008;4:235–8.

9 Veronese S, Gallo G, Valle A, *et al.* Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study. *BMJ Support Palliat Care*. 2017;7:164–72.

10 Oliver DJ. Palliative care in motor neurone disease: where are we now? *Palliat Care*. 2019;12:1178224218813914.

11 Oliver DJ, Borasio GD, Caraceni A, *et al.* A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurol*. 2016;23:30–8.

12 National Institute for Health and Clinical Excellence (NICE). Motor neurone disease: assessment and management. 2016. https://www.nice.org.uk/guidance/ng42 (accessed 13 December 2022)

13 McNamara B, Rosenwax LK, Holman CDJ. A method for defining and estimating the palliative care population. *J Pain Symptom Manage*. 2006;32:5–12.

14 Nair K, Lee M, Hobson E, *et al.* End-of-life care of people with long-term neurological conditions. *PRACT NEUROL*. 2022;22:385–91.

15 Ding J, Johnson CE, Qin X, *et al.* Palliative care needs and utilisation of different specialist services in the last days of life for people with lung cancer. *Eur J Cancer Care*. 2021;30. doi: 10.1111/ecc.13331

16 Palliative Care Australia. Palliative Care Service Development Guidelines. 2018. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf (accessed 8 May 2023)

17 Whitney RL, Bell JF, Tancredi DJ, *et al.* Hospitalization Rates and Predictors of Rehospitalization Among Individuals With Advanced Cancer in the Year After Diagnosis. *J Clin Oncol*. 2017;35:3610–7.

18 Kavalieratos D, Gelfman LP, Tycon LE, *et al.* Palliative Care in Heart Failure: Rationale, Evidence, and Future Priorities. *J Am Coll Cardiol*. 2017;70:1919–30.

19 Oliver D, Borasio GD, Johnston W, editors. *Palliative care in amyotrophic lateral sclerosis: from diagnosis to bereavement*. Third edition. Oxford: Oxford University Press 2014.

20 Palliative Care Outcomes Collaboration. Palliative Care Outcomes Collaboration Clinical Manual. 2021. https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf (accessed 24 February 2023)

21 Daveson B, Blanchard M, Clapham S, *et al.* Population-level, patient-reported outcomes: a case study regarding a public health intervention that involves patients with life-limiting illnesses. *Front Public Health*. 2023;11:1232881.

22 University of Wollongong. Palliative care outcomes collection. https://www.uow.edu.au/ahsri/pcoc/research-data/ (accessed 8 May 2023)

23 Aoun SM, Monterosso L, Kristjanson LJ, *et al.* Measuring Symptom Distress in Palliative Care: Psychometric Properties of the Symptom Assessment Scale (SAS). *Journal of Palliative Medicine*. 2011;14:315–21.

24 Masso M, Allingham SF, Johnson CE, *et al.* Palliative Care Problem Severity Score: Reliability and acceptability in a national study. *Palliat Med*. 2016;30:479–85.

25 Fries BE, Schneider DP, Foley WJ, *et al.* Refining a Case-Mix Measure for Nursing Homes: Resource Utilization Groups (RUG-III): *Medical Care*. 1994;32:668–85.

26 Abernethy AP, Shelby-James T, Fazekas BS, *et al.* The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliat Care*. 2005;4:7.

27 Masso M, Allingham SF, Banfield M, *et al.* Palliative Care Phase: Inter-rater reliability and acceptability in a national study. *Palliat Med*. 2015;29:22–30.

28 Australian Bureau of Statistics. SOCIO-ECONOMIC INDEXES FOR AREAS (SEIFA) 2016. 2023. https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~IRSAD~20 (accessed 27 April 2023)

29 Mc Veigh C, Donaghy C, Mc Laughlin B, *et al.* Palliative care for patients with motor neurone disease and their bereaved carers: a qualitative study. *BMC Palliat Care*. 2019;18:39.

30 Tiirola A, Korhonen T, Surakka T, *et al.* End-of-Life Care of Patients With Amyotrophic Lateral Sclerosis and Other Nonmalignant Diseases. *Am J Hosp Palliat Care*. 2017;34:154–9.

31 Gibbons CJ, Thornton EW, Young CA. The patient experience of fatigue in motor neurone disease. *Front Psychol*. 2013;4:788.

32 Miller RG, Jackson CE, Kasarskis EJ, *et al.* Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review). *Neurology*. 2009;73:1218–26.

33 Kamal AH, Currow DC, Ritchie CS, *et al.* Community-based palliative care: the natural evolution for palliative care delivery in the U.S. *J Pain Symptom Manage*. 2013;46:254–64.

34 Eagar K, Clapham SP, Allingham SF. Palliative care is effective: but hospital symptom outcomes superior. *BMJ Support Palliat Care*. 2020;10:186–90.

35 Clark K, Connolly A, Clapham S, *et al.* Physical Symptoms at the Time of Dying Was Diagnosed: A Consecutive Cohort Study To Describe the Prevalence and Intensity of Problems Experienced by Imminently Dying Palliative Care Patients by Diagnosis and Place of Care. *J Palliat Med*. 2016;19:1288–95.

36 de Graaf E, Zweers D, de Graeff A, *et al.* Symptom Intensity of Hospice Patients: A Longitudinal Analysis of Concordance Between Patients' and Nurses' Outcomes. *J Pain Symptom Manage*. 2018;55:272–81.

37 Aoun SM, Deas K, Kristjanson LJ, *et al.* Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool. *Palliat Support Care*. 2017;15:32–43.

38 Watermeyer TJ, Brown RG, Sidle KCL, *et al.* Impact of disease, cognitive and behavioural factors on caregiver outcome in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*. 2015;16:316–23.

39 Cheng HWB, Chan OMI, Chan CHR, *et al.* End-of-life Characteristics and Palliative Care Provision for Patients With Motor Neuron Disease. *Am J Hosp Palliat Care*. 2018;35:847–51.

40 Seow H, Barbera L, Sutradhar R, *et al.* Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. *J Clin Oncol*. 2011;29:1151–8.

41 Gwilliam B, Keeley V, Todd C, *et al.* Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ*. 2011;343:d4920.

42 Ding J, Cook A, Qin X, *et al.* 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.

43 Lerum SV, Solbraekke KN, Frich JC. Healthcare professionals' accounts of challenges in managing motor neurone disease in primary healthcare: a qualitative study. *Health Soc Care Community*. 2017;25:1355–63.

44 Warrier MG, Thomas PT, Sadasivan A, *et al.* Family Caregivers' Experiences with Dying and Bereavement of Individuals with Motor Neuron Disease in India. *J SOC WORK END-LIFE*. 2019;15:111–25.

45 Zwicker J, Qureshi D, Talarico R, *et al.* Dying of amyotrophic lateral sclerosis: Health care use and cost in the last year of life. *Neurology*. 2019;93:e2083–93.

46 Rosenwax L, Spilsbury K, McNamara BA, *et al.* A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? *BMC Palliat Care*. 2016;15:46.

47 Youens D, Moorin R. The Impact of 1on Utilization and Cost of Acute Care Hospital Services in the Last Year of Life. *Journal of Palliative Medicine*. 2017;20:736–44.

48 Olvera CE, Levin ME, Fleisher JE. Community-based neuropalliative care. *Handb Clin Neurol*. 2023;191:49–66.

49 Collis E, Al-Qurainy R. Care of the dying patient in the community. *BMJ*. 2013;347:f4085.

50 Australian Institute of Health and Welfare. Palliative care services in Australia, Palliative care workforce - Australian Institute of Health and Welfare. 2023. https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce (accessed 3 July 2023)

51 Brewah H, Borrett K, Tavares N, *et al.* Perceptions of people with motor neurone disease, families and HSCPs: a literature review. *Br J Community Nurs*. 2022;27:188–98.

52 Bentley B, O'Connor M. The End-of-Life Experiences of People with Motor Neuron Disease: Family Carers' Perspectives. *J PALLIAT MED*. 2016;19:857–62.

53 Miller RG, Jackson CE, Kasarskis EJ, *et al.* Practice Parameter update: The care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2009;73:1227–33.

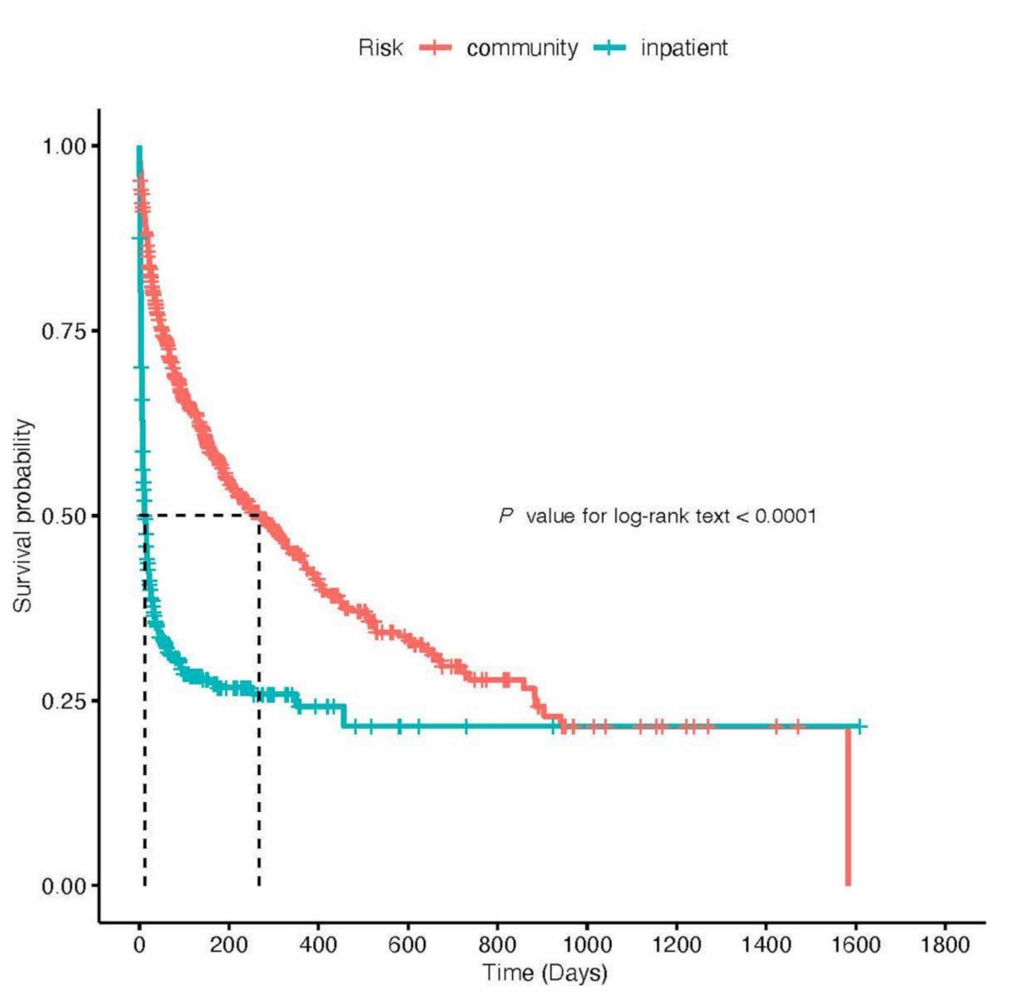

Figure 1. Survival curves for MND patients in inpatient versus community palliative care. Time (in days) is shown on the x-axis, and Survival Probability is shown on the y-axis. The log-rank test was used to compare the survival curves between the two groups. Notably, inpatients had a much shorter time interval between palliative care admission and death compared to the community care group (P < 0.0001).

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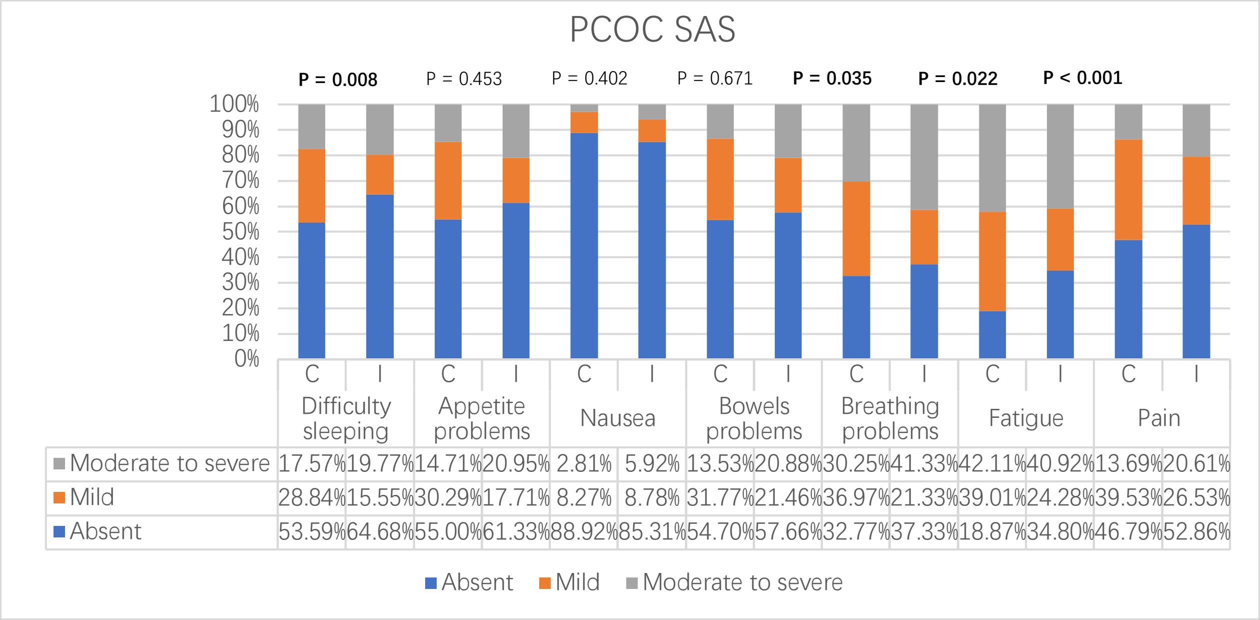
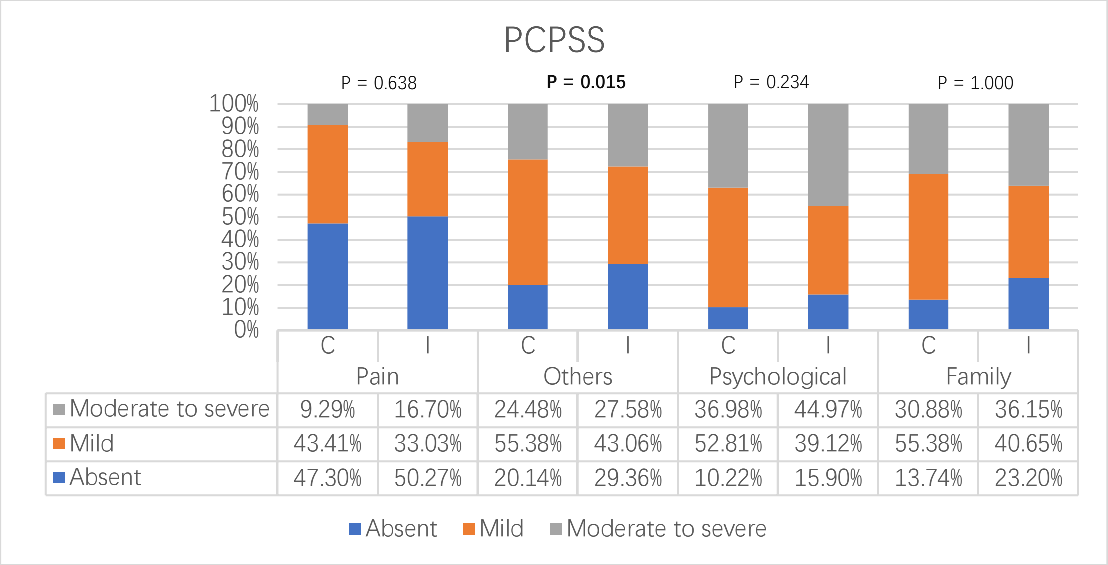


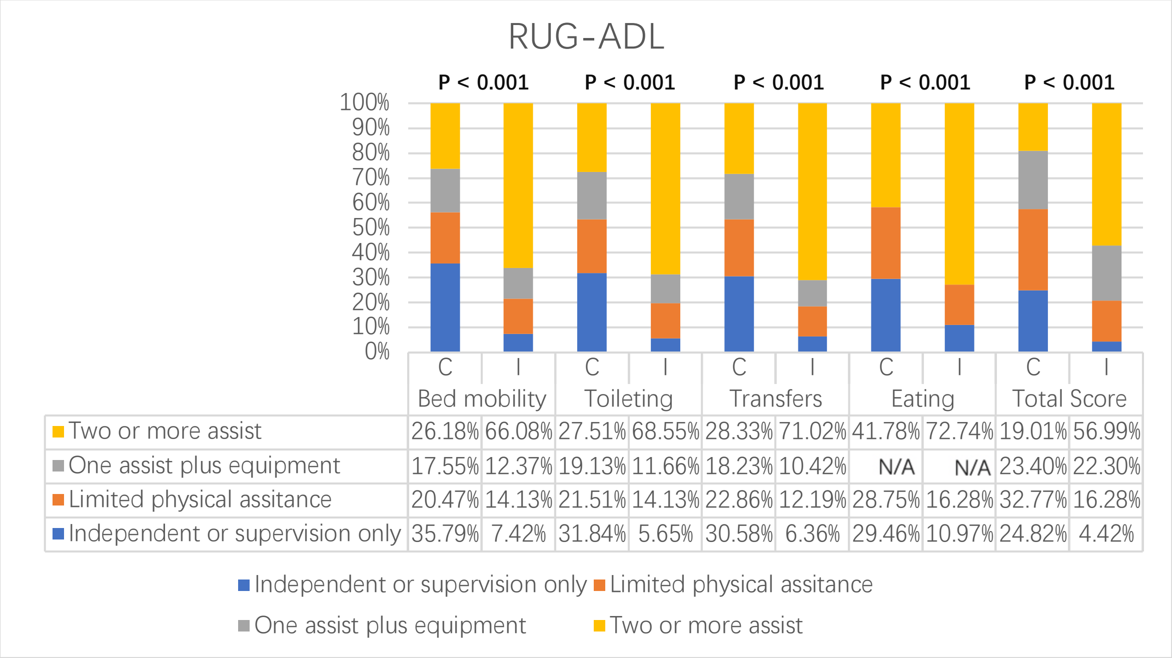
	Difficulty sleeping C	Difficulty sleeping I	Appetite problems C	Appetite problems I	Nausea C	Nausea I	Bowels problems C	Bowels problems I	Breathing problems C	Breathing problems I	Fatigue C	Fatigue I	Pain C	Pain I
■ Moderate to severe	17.57%	19.77%	14.71%	20.95%	2.81%	5.92%	13.53%	20.88%	30.25%	41.33%	42.11%	40.92%	13.69%	20.61%
■ Mild	28.84%	15.55%	30.29%	17.71%	8.27%	8.78%	31.77%	21.46%	36.97%	21.33%	39.01%	24.28%	39.53%	26.53%
■ Absent	53.59%	64.68%	55.00%	61.33%	88.92%	85.31%	54.70%	57.66%	32.77%	37.33%	18.87%	34.80%	46.79%	52.86%

Figure S1. *Distribution for levels of distress associated with patient-reported SAS symptoms*



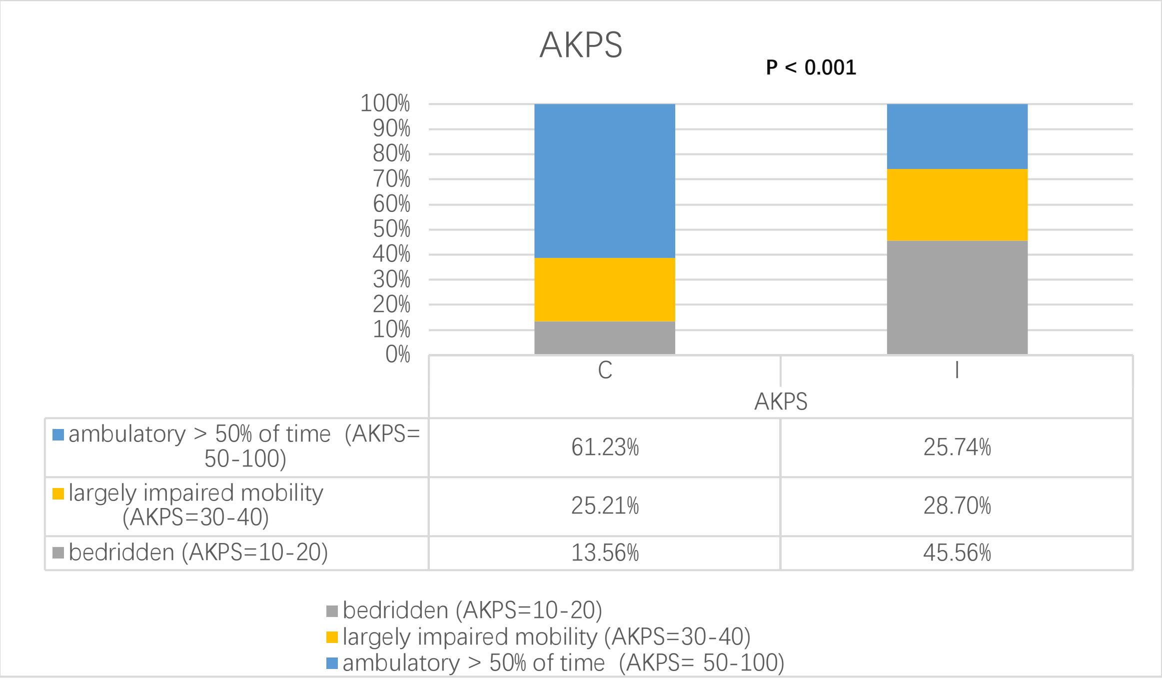
	Pain C	Pain I	Others C	Others I	Psychological C	Psychological I	Family C	Family I
■ Moderate to severe	9.29%	16.70%	24.48%	27.58%	36.98%	44.97%	30.88%	36.15%
■ Mild	43.41%	33.03%	55.38%	43.06%	52.81%	39.12%	55.38%	40.65%
■ Absent	47.30%	50.27%	20.14%	29.36%	10.22%	15.90%	13.74%	23.20%

Figure S2. *Distribution for levels of clinician-rated palliative care problems*



	Bed mobility C	Bed mobility I	Toileting C	Toileting I	Transfers C	Transfers I	Eating C	Eating I	Total Score C	Total Score I
🟨 Two or more assist	26.18%	66.08%	27.51%	68.55%	28.33%	71.02%	41.78%	72.74%	19.01%	56.99%
⬜ One assist plus equipment	17.55%	12.37%	19.13%	11.66%	18.23%	10.42%	N/A	N/A	23.40%	22.30%
🟧 Limited physical assitance	20.47%	14.13%	21.51%	14.13%	22.86%	12.19%	28.75%	16.28%	32.77%	16.28%
🟦 Independent or supervision only	35.79%	7.42%	31.84%	5.65%	30.58%	6.36%	29.46%	10.97%	24.82%	4.42%

Figure S3. *Distribution for levels of clinician-rated level of dependency*



	AKPS C	AKPS I
🟦 ambulatory > 50% of time (AKPS= 50-100)	61.23%	25.74%
🟨 largely impaired mobility (AKPS=30-40)	25.21%	28.70%
⬜ bedridden (AKPS=10-20)	13.56%	45.56%

Figure S4. *Distribution for levels of clinician-rated performance status*

For figures S1-4:

Abbreviations: C: Community patients; I: Inpatients

Comparisons of distributions between community patients and inpatients were performed using Pearson' s Chi-square test

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4，5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5，6
Bias	9	Describe any efforts to address potential sources of bias	13,14
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6，7
		(*b*) Describe any methods used to examine subgroups and interactions	Not applicable
		(*c*) Explain how missing data were addressed	8
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	5
		(*e*) Describe any sensitivity analyses	Not applicable
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	5
		(b) Give reasons for non-participation at each stage	Not applicable
		(c) Consider use of a flow diagram	Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7-8
		(b) Indicate number of participants with missing data for each variable of interest	7-8
Outcome data	15*	Report numbers of outcome events or summary measures	7-11
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	10,11
		(*b*) Report category boundaries when continuous variables were categorized	7,8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Not applicable
Discussion			
Key results	18	Summarise key results with reference to study objectives	11-13
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13,14
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Palliative care needs and utilization of specialist services for people diagnosed with motor neurone disease: A national population-based study

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Primary Subject Heading:	Palliative care
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Keywords:	PALLIATIVE CARE, Health Services, Motor neurone disease < NEUROLOGY, Nursing Care

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TITLE PAGE

Title: Palliative care needs and utilization of specialist services for people diagnosed with motor neurone disease: A national population-based study

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Abstract

Introduction: There is a growing emphasis on the importance of the availability of specialist palliative care for people with motor neurone disease (MND). However, the palliative care needs of this population and utilization of different specialist services remain poorly defined.

Objectives: To (i) describe clinical characteristics, symptom burden and functional levels of patients dying with MND upon their admission to palliative care services; (ii) determine factors associated with receiving inpatient or community palliative care services.

Design: An observational study based on point-of-care assessment data from the Australian Palliative Care Outcomes Collaboration (PCOC).

Participants: A total of 1,308 patients who received palliative care principally because of MND between 1 January 2013 and 31 December 2020.

Measures: Five validated clinical instruments were used to assess each individual's function, distress from symptoms, symptom severity and urgency, and acuity of their condition.

Results: Most MND patients had no or mild symptom distress, but experienced a high degree of functional impairment. Patients who required "two assistants for full care" relative to those who were "independent" (odds ratio = 11.53, 95% confidence interval: 4.87–27.26) and those in "unstable" relative to "stable" palliative care phases (odds ratio =16.74, 95% confidence interval: 7.73– 36.24) were more likely to use inpatient versus community-based palliative care. Associations between the use of different palliative care services and levels of symptom distress were not observed in this study.

Conclusions: Patients with MND were more likely to need assistance for decreased function and activities of daily living, rather than symptom management. This population could have potentially been cared for in the palliative phase in a community setting if greater access to supportive services were available in this context.

Keywords

palliative care, motor neurone disease, Nursing Care, Health Services

Strengths and limitations of this study

⇒ A major strength of this study lies in its large sample size, which was based on national population data, and relatively long period of data collection (2013 – 2020).

⇒ People with motor neurone disease in the palliative phase could potentially have been cared for in a community setting if greater access to supportive services were available.

⇒ The PCOC data may not fully capture information on particular patient characteristics and clinical needs that may influence their utilization of different types of palliative care services.

Introduction

Motor neurone disease (MND) is a neurodegenerative condition that progressively affects the brain and spinal cord, often leading to significant physical impairment and, in some cases, a locked-in state toward the end of life[1,2]. In Australia, it is estimated that approximately 2,100 individuals are living with MND[3] and, on average, two people die from the condition each day[4]. The average life expectancy from the time of diagnosis varies and can range from two to five years or longer, depending on the severity and muscle groups affected by the disease[5]. As the illness progresses, many people living with MND experience a wide range of constantly changing care needs[1]. The UK's National Service Framework for Long-Term Conditions advocates life-long care for people diagnosed with long-term neurological conditions (LTNC) - including MND - and recommends an integrated approach involving neurology, rehabilitation and palliative care to address the diagnostic, restorative and palliative phases of illness[6].

Palliative care is defined as a multidisciplinary care approach to improve the quality of life for individuals facing life-limiting conditions and their families[7]. In recent years, there has been a growing recognition of the need for palliative care to be made available to all patients nearing the end of life, irrespective of their diagnosis, including those affected by MND[8]. Extensive research has shown the value of palliative care for people diagnosed with MND in alleviating clinical symptoms such as pain, dyspnea, sleep disturbances and bowel symptoms, as well as improving the quality of life for both patients and their families[9–12]. However, non-malignant diseases such as MND are still under-represented in palliative care[13]. Although various palliative care strategies have been formulated, their applicability to people with MND is limited due to the unique palliative care requirements and disease trajectory[14]. Therefore, there is a need to optimize palliative care for people with MND by providing the 'right care in the right place at the right time'.

Palliative care in Australia is recognized internationally for its quality and accessibility[15]. Community-based palliative care (CPC) and inpatient palliative care (IPC) services are two essential settings of care that have different processes, structures and resourcing, and both are critical in providing palliative care. People living with a life-limiting illness should be able to access palliative care in different settings, depending on the complexity of their needs and preferences. Australian data indicate that approximately 50% of people die in hospitals (which includes people in IPC units), while the remaining 50% of people die in community settings. Some people's preferences for setting of care and death change after they are diagnosed with a life-limiting illness as their illness progresses or if their circumstances change[16]. Compared to inpatient options, CPC significantly improves symptom management and quality of life while reducing healthcare utilization and costs for people at the end of life [17]. Community-based management can provide longitudinal support to patients and their families in different settings, making care more affordable and accessible [18]. However, people with complex and acute care needs may often require and should have ready access to IPC.

There is increasing awareness of the role of palliative care for people diagnosed with neurological disorders[11], specifically for those with MND[10,12,19]. However, little evidence on the factors related to the utilization of different specialist services during the last few days of life has been reported. Such knowledge would enable the evaluation of whether individuals dying with MND receive the 'right care in the right place' and would also enhance care, and inform policy development, resource allocation and personnel training. This study aimed to (a) describe the symptom burden and level of function of people with MND on their first admission to IPC and CPC before death, and (b) determine factors associated with receiving inpatient or community palliative care services.

Methods

Study design and data sources

De-identified, point-of-care assessment data were collected by the Australian Palliative Care Outcomes Collaboration (PCOC) [20], a voluntary national program focused on improving the quality and outcomes in palliative care. The PCOC program, which is funded by the Australian Government Department of Health and Aged Care, evaluates patients in inpatient and community settings across various models of care. Any service in Australia that provides palliative care can participate in PCOC. The number of deaths reported in PCOC increased each year both in absolute terms and as a percentage of patients who might potentially benefit from palliative care (14.8% to 25.1%). In 2012, the national initiative reported 16,358 deaths, which increased to 32,421 deaths in 2022[21]. The Palliative Care Outcomes Collaboration's dataset collects demographic, setting and clinical assessment information for palliative care patients and now comprises data describing more than 250,000 patients[22]. Inpatient palliative care services conduct detailed assessments of individual patients upon admission and then at least daily and at phase change. Community palliative care services perform assessments on admission and during each subsequent encounter (e.g. each visit) either in-person or by telephone/telehealth[22]. Data related to admission, phase changes and discharge are reported to PCOC biannually. Before data are analyzed, the PCOC program conducts a review and data cleaning process. Participating services receive six-monthly reports on their performance which allows comparisons with national results and performance benchmarks established against industry standards.

Patient and public involvement

There was no direct patient or public involvement in this study.

Population and setting

This study included patients who met the following criteria: (i) required specialist palliative care from one or more of the services across Australia registered in PCOC; (ii) required palliative care principally for MND; (iii) with a first episode of care occurring between 1 January 2013 and 31 December 2020; and (iv) death occurring between 1 January 2013 and 31 December 2020. Two types of specialist palliative care episodes were included in this study: community and inpatient (including consult liaison services). An 'inpatient episode' refers to patients who have been seen in designated specialist palliative care units as well as in non-palliative care designated beds by specialist palliative care consultants/teams. A 'community episode' refers to people who receive specialist palliative care at private residences or residential care facilities[20]. The term 'episode of care' is defined as a continuous period of care for a patient in one setting. An episode of care ends when the setting of care changes.

Variables and instruments

Five validated clinical instruments were used to assess clinical outcomes[20]. Levels of distress from symptoms (i.e. difficulties with sleeping, appetite, nausea, bowel symptoms, breathing problems, fatigue, and pain) were assessed using the 11-point Symptoms Assessment Scale (PCOC SAS) (0 – absent; 10 – worst possible distress)[23]. The PCOC SAS is ideally rated by the patient, but rating by proxies (i.e. family or clinicians) is permitted if the patient loses the capacity of self-assessment. The severity of patients' palliative care problems (pain, other symptoms, psychological/spiritual, and family/career concerns) were evaluated using the clinician-rated, four-point Palliative Care Problem Severity Score (PCPSS) (0–absent; 3–severe)[24]. Patients' level of functional dependency (eating, toileting, bed mobility, and transfers) were rated using the Resource Utilisation Groups - Activities of Daily Living (RUG-ADL) which scores eating based on a three-point item (1–independent or supervision only; 3–total dependence/tube fed), and the other three activities (toileting, bed mobility, and transfers) with five-point items (1–independent; 5–two or more persons assist)[25]. Performance status was determined by the 11-point Australia-modified Karnofsky Performance Status (AKPS) (0–dead; 100–complete function)[26]. The non-sequential Palliative Care Phase (Stable, Unstable, Deteriorating, or Terminal) is a holistic assessment of patients and their carers (including families) palliative needs and concerns[27]. The latter four of the tools were designed to be rated by trained clinicians.

Other clinical and socio-demographic characteristics involved in the study included sex, age, preferred language, length of admission, length of palliative care stay, referral source, accommodation at the start of the episode and place of death. A summary measure of social and economic conditions, the Socio-Economic Indexes for Areas (SEIFA) [28], was also included. This indicator, developed by the Australian Bureau of Statistics, ranks areas in Australia according to relative socio-economic advantage and disadvantage with scores ranging from 1 (very high levels of disadvantage) to 10 (very low levels of disadvantage).

This study focused on the first assessment conducted on admission to the inpatient or community care setting that occurred during the first episode of care for each patient. The variable 'end mode of the first episode' refers to the reason why the first episode of palliative care came to an end and 'death' is one of the categories within this variable.

Data analysis

Characteristics of participants and episodes were described using frequencies and percentages. Standard clinical measures (RUG-ADL, AKPS, PCPSS, and SAS) were presented using means (standard deviation, SD) and medians (with interquartile range, IQR). Differences between the two types of specialist palliative care episodes (community and inpatient) were assessed using Pearson's chi-square tests (characteristics of participants and episodes) and Mann–Whitney U tests (length of stay and standard clinical measures)

Multivariable logistic regression analyses were conducted to identify factors associated with receiving inpatient or community palliative care services. Factors significantly associated with utilization of different specialist services were determined by using stepwise procedures. Multicollinearity was assessed using variance inflation factors (VIF). In our multivariate models, inclusion and exclusion criteria were set at significance levels of 0.05 and 0.10, respectively. We also utilized C-index to assess the fitness of the final model. Due to the high level of correlation within elements of the RUG-ADL family, we only selected "Total RUG-ADL" for the stepwise procedures. *P*-values for trend were calculated for the following variables: age, days until death, and scores of symptoms and function. Patients receiving community services were used as the reference group.

In the regression analyses, PCOC SAS, PCPSS, total RUG-ADL, and AKPS were coded as categorical variables based on different clinical levels as follows: (i) Scores on PCOC SAS were classified as: 0 = absent (corresponding to PCOC SAS = 0), 1 = mild (PCOC SAS = 1–3), 2 = moderate to severe (PCOC SAS = 4–10); (ii) PCPSS was classified as follows: for PCPSS: 0 = absent (corresponding to PCPSS = 0), 1 = mild (PCPSS = 1), 2 = moderate to severe (PCPSS = 2–3); (iii) for AKPS: 1 = ambulatory > 50% of the time (corresponding to AKPS = 50–100), 2 = largely impaired mobility (AKPS = 30–40), 3 = bedridden (AKPS = 10–20). (iv) for RUG-ADL: 1 = independent (corresponding to total RUG-ADL = 4–5), 2 = limited physical assistance (total RUG-ADL = 6–13), 3 = requires one assistant plus equipment (total RUG-ADL = 14–17), 4 = requires two assistants for full care (total RUG-ADL = 18).

We fitted Kaplan-Meier curves and performed log-rank tests to compare survival time after admission between the two groups. Survival time was defined as the interval between the date of first admission to a palliative care service to the date of death with a censor date of 31 December 2020.

Descriptive statistic estimation, logistic regression analyses, and collinearity analysis were performed using SPSS 26.0. The C-index and Kaplan-Meier curves were estimated using R statistical software version 4.0. *P*-values < 0.05 were considered statistically significant.

Results

Study population

A total of 1,308 people with MND were included in this study with 56.4% (738) accessing palliative care in a community setting and 43.6% (570) in an inpatient setting. A total of 54.4% were male, 34.9% were <65 years of age and 92.7% were from English-speaking backgrounds. More than 50% lived in areas with SEIFA category > 6. There were no statistically significant differences between the two groups for these sociodemographic characteristics. The specific sociodemographic and clinical characteristics for people with MND are shown in Table 1.

Table 1 Baseline sociodemographic and clinical characteristics for people with MND by episode settings

Characteristics of Patients	**All N (%)**	**Community *N* (%)**	**Inpatient *N* (%)**	***p*-values for differences by setting**
Sociodemographic characteristics				
Total number	1308	738(56.4)	570(43.6)	-
Sex				
Male	712(54.4)	417(56.5)	295(51.8)	0.087
Female	596(45.6)	327(43.5)	275(48.2)	
Age				
< 65 years	457(34.9)	264(35.8)	193(33.9)	0.660
65-75 years	474(36.2)	260(35.2)	214(37.5)	
> 75 years	377(28.8)	214(29.0)	163(28.6)	
Preferred language				
English	1212(92.7)	682(92.4)	530(93.0)	0.695
Non-English	96(7.3)	56(7.6)	40(7.0)	
SEIFA				
1-2	183(14.0)	104(14.1)	79(13.9)	0.994
3-4	143(11.0)	79(10.7)	64(11.2)	
5-6	225(17.2)	128(17.4)	97(17.1)	
7-8	324(24.8)	181(24.5)	143(25.2)	

9-10	431(33.0)	246(33.3)	185(32.6)	
Characteristics of Episodes of Care				
Years of admission				
2013	127(9.7)	64(8.7)	63(11.1)	0.202
2014	121(9.3)	62(8.4)	59(10.3)	
2015	150(11.5)	81(11.0)	69(12.1)	
2016	187(14.3)	102(13.8)	85(14.9)	
2017	186(14.2)	116(15.7)	70(12.3)	
2018	198(15.1)	113(15.3)	85(14.9)	
2019	202(15.4)	126(17.1)	76(13.3)	
2020	137(10.5)	74(10.0)	63(11.1)	
Referral source				
Hospital	468(35.8)	215(29.1)	253(44.4)	<0.001*
Community service	556(42.5)	311(42.1)	245(43.0)	
Others	86(6.6)	75(10.2)	11(1.9)	
Missing	198(15.1)	137(18.6)	61(10.7)	
Accommodation at the start of episode				
Private residence	1035(79.1)	616(83.5)	419(73.5)	<0.001*
Residential aged care	116(8.9)	85(11.5)	31(5.4)	
Other	36(2.7)	22(3.0)	14(2.5)	
Missing	121(9.3)	15(2.0)	106(18.6)	
Phase type on admission				
Stable	393(30.0)	303(41.1)	90(15.8)	<0.001*
Unstable	255(19.5)	26(3.5)	229(40.2)	
Deteriorating	588(45.0)	395(53.5)	193(33.8)	
Terminal	72(5.5)	14(1.9)	58(10.2)	
Days until death				
≤1week	293(22.4)	54(7.3)	239(41.9)	<0.001*
1 week~1 month	259(19.8)	118(16.0)	141(24.7)	
1 month~3 month	254(19.4)	161(21.8)	93(16.3)	
3 month~6 month	192(14.7)	141(19.1)	51(9.0)	
>6 month	310(23.7)	264(35.8)	46(8.1)	
The end mode of the first episode				
Death	764(58.4)	370(50.2)	394(69.1)	<0.001*
Others	528(40.4)	353(47.8)	175(30.7)	
Missing	16(1.2)	15(2.0)	1(0.2)	
Place of death				
Home	283(21.6)	283(38.3)	0(0.0)	<0.001*
Residential Aged Care Facility	76(5.8)	76(10.3)	0(0.0)	
Hospital	282(21.6)	0(0.0)	282(49.5)	
Unknown	667(51.0)	379(51.4)	288(50.5)	

Abbreviations: N/A: Not applicable.
NOTE. * indicates significant value p < 0.05.
Comparisons between the two groups were conducted using Pearson's chi-square tests. Missing data entries were not accounted for in the analyses.

Episode of care characteristics

On average, inpatients had a much shorter interval between palliative care admission and death compared to the individuals in the community care group (31 days vs. 249 days; P < 0.0001) (Figure 1). Compared to CPC patients, the inpatient group had a higher proportion of referrals from hospitals (44.4% vs. 29.1%), and a lower percentage of individuals living in private residences before the episode of care (73.5% vs. 83.5%, *p*<0.001). Community episodes most commonly commenced with a "stable" (41.1%) or "deteriorating" phase (53.5%), whereas inpatient episodes most frequently started with an "unstable" phase (40.2%) or "deteriorating" phase (33.9%) (*p*<0.001). The community group had a greater time between palliative care admission and death compared to the patients in the hospital (249 days vs. 31 days) (*p*<0.001). The majority of people with MND (35.8%) in CPC survived more than 6 months while half (49.1%) of inpatients survived less than 1 week (*p*<0.001).

Comparisons of standard clinical measures between the two groups

Table 2 indicates that RUG-ADL scores of people with MND in CPC were significantly lower than those of inpatients (11.28 vs. 15.66, *p* < 0.001), and the AKPS score was significantly higher (46.08 vs. 32.27, *p* < 0.001). As indicated in the PCOC SAS scores, the two highest levels of distress were reported concerning fatigue and breathing in both groups. The PCOC SAS scores for nausea in CPC were lower than in IPC (0.29 vs. 0.51, *p* = 0.042), as were scores related to breathing problems (2.56 vs. 3.13, *p* = 0.035) and pain (1.46 vs. 1.71, *p* < 0.001). Insomnia scores (1.58 vs. 1.54, *p* = 0.008) and fatigue scores (3.29 vs. 2.97, *p* = 0.022) were higher in CPC than in IPC. Appetite scores did not show significant difference across groups (1.44 vs. 1.53, *p* = 0.453). Nausea was the least prevalent symptom in both groups. For the scores on the PCPSS assessment, the pain domain was rated the lowest, and the "other symptoms" group was the highest. There were no statistical differences between the two groups except for the scores on the "other symptoms" category.

Table 2 Clinical outcome measures for patients with MND by episode settings

Clinical outcomes	N (patients)	All mean (SD) median (IQR)	Community mean (SD) median (IQR)	Hospital mean (SD) median (IQR)	p -values for differences by settings *
AKPS	1270	40.11(16.82) 40(20,50)	46.08(0,62) 50(40,50)	32.27(0.69) 30(20,50)	<0.001*
RUG-ADL					
Total RUG-ADL	1270	13.25(5.13) 15(10,18)	11.28(0.21) 12(6,16)	15.66(0.17) 18(14,18)	<0.001*
Transfer	1279	3.70(1.53) 4(3,5)	3.13(0.06) 3(1,5)	4.39(0.05) 5(4,5)	<0.001*
Mobility	1284	3.56(1.59) 4(3,5)	2.94(0.07) 3(1,5)	4.29(0.05) 5(4,5)	<0.001*
Toileting	1282	3.67(1.53) 4(3,5)	3.08(0.07) 3(1,5)	4.36(0.05) 5(4,5)	<0.001*
Eating	1271	2.34(0.81) 3(2,3)	2.13(0.03) 2(1,3)	2.62(0.03) 3(2,3)	<0.001*
PCPSS					
Pain	1278	0.65(0.73) 1(0,1)	0.61(0.03) 1(0,1)	0.70(0.04) 0(0,1)	0.638
Other symptoms	1242	1.36(0.80) 1(1,2)	1.31(0.03) 1(1,2)	1.38(0.04) 1(1,2)	0.015*
Psychological	1277	1.07(0.81) 1(1,2)	1.08(0.03) 1(1,1)	1.01(0.04) 1(0,2)	0.234
Family	1262	1.220.81) 1(1,2)	1.20(0.03) 1(1,2)	1.23(0.04) 1(1,2)	1.000
PCOC SAS					
Difficulty sleeping	1204	1.57(2.34) 0(0,3)	1.58(0.09) 0(0,3)	1.54(0.12) 0(0,3)	0.008*
Appetite problems	1225	1.54(2.31) 0(0,3)	1.44(0.09) 0(0,2)	1.53(0.11) 0(0,3)	0.453
Nausea	1237	0.39(1.32) 0(0,0)	0.29(0.05) 0(0,0)	0.51(0.07) 0(0,0)	0.042*
Bowels problems	1224	1.48(2.16) 0(0,2)	1.30(0.08) 0(0,2)	1.58(0.11) 0(0,3)	0.671
Breathing problems	1239	2.81(2.84) 2(0,5)	2.56(0.10) 2(0,4)	3.13(0.15) 2(0,5)	0.035*
Fatigue	1233	3.22(2.75) 3(0,5)	3.29(0.10) 3(1,5)	2.97(0.14) 2(0,5)	0.022*
Pain	1240	1.58(2.14) 1(0,2)	1.46(0.08) 1(0,2)	1.71(0.11) 0(0,3)	<0.001*

Abbreviations: SD: Standard deviation, IQR: interquartile range, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, PCOC SAS: Symptom Assessment Scale.
NOTE. ***** indicates significant value *p* < 0.05.
Comparisons between the two groups were conducted using the Mann–Whitney U test.

Factors associated with the utilization of different specialist palliative care services

The final regression model (table 3) had a high C-statistic of 0.89 and included the following variables: age groups, sex, admission year, referral source, episode start accommodation, days until death, phase type, SAS appetite, PCPSS-pain, PCPSS-other symptoms, PCPSS-family, and RUG-ADL Total.

In the adjusted model, lower odds for entry into IPC were observed for people with MND who were accommodated at residential aged care facilities versus private residences (OR = 0.24; 95% CI: 0.12-0.49, p < 0.001) and for those who had longer survival times after palliative care admission (ORs ranged from 0.02 to 0.18, p < 0.001 for all) versus less than 1 week of survival. Compared to those in the “stable” phase, people with MND in an “unstable” phase had increased odds for utilization of IPC versus CPC (OR = 16.74; 95% CI: 7.73-36.24, p < 0.001). Higher levels of dependency (ORs ranged from 3.56 to 11.33, p < 0.05 for all estimates) also predicted higher odds for IPC utilization. For PCPSS, relative to “absent” as the reference category, individuals with “mild” level of pain problems had lower odds of receiving IPC (OR = 0.58; 95% CI: 0.37-0.93, p < 0.05); a similar trend was observed for those with “mild” and “moderate/severe” levels of family concern (ORs ranged from 0.35 to 0.36; p < 0.05 for both).

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

	Inpatient vs community unadjusted OR (95%CI, p-value [a]	Inpatient vs community adjusted OR (95%CI, p-value) [b]	P for trend
Characteristics of patients and episodes of care			
Age groups (Ref. <65 years)			
65-75 years	1.13(0.87-1.46; 0.37)	1.50(0.89-2.53; 0.13)	0.734
> 75 years	1.04(0.79-1.37;0.77)	0.90(0.52-1.56; 0.72)	
Sex (Ref. male)	1.21(0.97-1.51; 0.09*)	1.13(0.74-1.73; 0.59)	
Admission of year (Ref. 2013)			
2014	0.97(0.59-1.59; 0.89)	1.04(0.42-2.60; 0.93)	0.050*
2015	0.87(0.54-1.39; 0.55)	0.43(0.17-1.09; 0.08)	
2016	0.85(0.54-1.33; 0.47)	0.36(0.15-0.86; 0.02*)	
2017	0.61(0.39-0.97; 0.04*)	0.33(0.13-0.83; 0.02*)	
2018	0.76(0.49-1.20; 0.24)	0.41(0.17-0.97; 0.04*)	
2019	0.61(0.39-0.96; 0.03*)	0.38(0.16-0.93; 0.03*)	
2020	0.87(0.53-1.40; 0.56)	0.41(0.16-1.03; 0.06)	
Referral source (Ref. hospital)			
Community service	0.67(0.52-0.86; 0.001*)	1.32(0.84-2.07; 0.23)	
Others	0.13(0.07-0.24; <0.001*)	0.32(0.09-1.22; 0.10)	
Episode start accommodation (Ref. private residence)			
Residential aged care	0.54(0.35-0.82; 0.004*)	0.24(0.12-0.49; <0.001*)	
Other	0.94(0.47-1.85; 0.85)	1.32(0.35-4.95; 0.68)	
Days until death (Ref. ≤ 1 week)			
1 week ~ 1 month	0.27(0.18-0.40; <0.001*)	0.18(0.09-0.34; <0.001*)	<0.001 *
1 month ~ 3 months	0.13(0.09-0.19; <0.001*)	0.08(0.04-0.16; <0.001*)	
3 month ~ 6 months	0.08(0.05-0.13; <0.001*)	0.07(0.03-0.15; <0.001*)	
＞6 months	0.04(0.03-0.06; <0.001*)	0.02(0.01-0.04; <0.001*)	
Clinical measures			
Phase type (Ref. stable)			
Unstable	29.65(18.55-47.39; <0.001*)	16.74(7.73-36.24; <0.001*)	
Deteriorating	1.65(1.23-2.20; 0.001*)	0.68(0.40-1.15; 0.15)	
Terminal	13.95(7.43-26.17; <0.001*)	0.70(0.23-2.07; 0.52)	
SAS appetite (Ref. absent)			

Mild	0.53(0.39-0.70; <0.001*)	0.86(0.50-1.46; 0.57)	0.983
Moderate/severe	1.28(0.94-1.74; 0.12)	1.78(0.99-3.22; 0.06)	
PCPSS-pain (Ref. absent)			
Mild	0.72(0.56-0.91; 0.007*)	0.58(0.37-0.93; 0.03*)	0.258
Moderate/severe	1.69(1.19-2.40; 0.003*)	0.78(0.39-1.57; 0.49)	
PCPSS-family (Ref. absent)			
Mild	0.44(0.32-0.59; <0.001*)	0.36(0.20-0.64; 0.001*)	0.290
Moderate/severe	0.69(0.50-0.96; 0.03*)	0.35(0.18-0.67; 0.002*)	
PCPSS-other symptoms (Ref. absent)			
Mild	0.48(0.33-0.68; <0.001*)	1.07(0.54-2.12; 0.84)	0.550
Moderate/severe	0.78(0.55-1.12; 0.18)	0.60(0.29-1.24; 0.17)	
RUG-ADL Total (Ref. independent)			
Limited physical assistance	2.79(1.72-4.52; <0.001*)	2.23(0.98-5.19 0.06)	<0.001 *
Requires one assistant plus equipment	5.35(3.31-8.63; <0.001*)	3.65(1.54-8.65; 0.003*)	
Requires two assistants for full care	16.82(10.57-26.78; <0.001*)	11.53(4.87-27.26; <0.001*)	

Abbreviations: OR: odds ratios, CI: confidence interval, RUG-ADL: Resource Utilization Group-Activities for Daily Living, AKPS: Australian-modified Karnofsky Performances Status, PCPSS: Palliative Care Problem Severity Score, Ref.: reference.

[a] Unadjusted and adjusted OR values estimated based on univariate and multivariate binary logistic regression models. Patients admitted to community palliative care were used as the reference group.

[b] Adjusted models include all variables selected through stepwise procedures; unadjusted models include each specific variable.

OR values are calculated based on transformed categorical variables. Reference category for RUG-ADL Total: requires less than two assistants; for AKPS: not completely bedfast; for PCPSS and PCOC SAS: Absent.

* indicates significant value $p < 0.05$.

Discussion

This study assessed the palliative care needs and other clinical characteristics of individuals accessing palliative care principally for MND and explored factors associated with receiving inpatient or community palliative care services. Overall, the majority of people with MND had low levels of symptom distress identified using the PCOC SAS, but relatively high levels of functional impairment. Disparities in symptom distress and severity between the groups were not consistently associated with the utilization of IPC versus CPC, whereas individuals with higher dependence were more likely to access IPC versus CPC. Patterns of use of the different types of palliative care services were also highly associated with the palliative care phase and variables such as accommodation type prior to accessing the palliative care and days until death.

In our study, symptom scores for both groups were mostly categorized as “absent” or “mild” (supplementary material figures S1–S2). Higher levels of distress (ranging from moderate to severe) from fatigue and breathing problems were reported relative to other symptoms. Previous studies of people with MND have reported that both of these symptoms are prevalent and often incapacitating [29,30]. Fatigue, which manifests as reversible motor weakness and feelings of intense fatigue throughout the entire body, is only partially alleviated by rest[31]. Moreover, respiratory failure is often the primary cause of death in many people with MND[32], and our study (similar to other studies) highlights the importance of implementing interventions that can help improve symptom control related to respiratory insufficiency and fatigue.

We also found that the level of symptom distress experienced by people with MND was not associated with the setting of specialist palliative care. These findings are consistent with previous studies of lung cancer patients conducted by Ding [15]. Although previous studies have reported better symptom outcomes for patients receiving inpatient versus community services[33–35], it is important to clarify whether inpatient care offers particular advantages in symptom management for the majority of people with MND in their final stage of life.

The observed associations between use of IPC and lower levels of family concerns and pain are unexpected. This is may be attributable to closer contact between families caring for their patient and CPC providers[15] in the home-care environment enabling them to better identify family/care-related distress[36]. In addition, the burden of hands-on care on family caregivers at home is substantial, especially when individuals are physically disabled and when their condition is deteriorating[37–39]. Given that the assessments of people included in the study were carried out upon their first admission to palliative care services, the patient's family may - as a result of the patient's entry to IPC - experience a reduction in distress and partial relief from the burden of caring. The underlying reasons for the unexpected association between IPC and lower levels of pain need further exploration, while also noting that the nature and intensity of pain is highly variable with MND and its complications.

This study emphasized the contrasts in function and performance between the two groups of people with MND. The majority of people admitted to IPC required substantial assistance with daily living tasks (with mean RUG-ADL total scores >13), whereas those admitted to CPC typically needed more limited assistance (supplementary material figure S3). The AKPS results suggest that around 39% of individuals receiving community care experienced impairment in mobility, compared to 74% of inpatients (supplementary material figure S4). Additionally, inpatients had a much shorter time between palliative care admission and death compared to the individuals in the community care group (31 vs. 249 days). These findings suggest that the functional status at initiation of palliative care is a significant prognostic predictor in patients with MND, which aligns with previous studies on patients with cancer and dementia [15,40–42].

Our adjusted analyses revealed that individuals with high levels of dependency were more likely to utilize inpatient services compared to community-based services. Family caregivers [43] often face considerable challenges in caring for people with MND at home, especially when the patient deteriorates or becomes clinically unstable[44]. Inpatient services, which provide highly specialized management 24 hours a day, can provide support for patients and their families in these circumstances[33]. Notably, nearly 74% of inpatients lived in private residences before admission, and 43% were referred from a community service. In terms of service delivery, these findings raise the importance of providing greater levels of community-based support for families during periods of patient deterioration and prior to death, which may potentially allow some people to remain in the home environment.

Given the incurable nature of MND and the level of debility as an individual deteriorates, healthcare costs and hospital-based care tend to be significantly higher relative to other conditions [45]. Early access to palliative care services to maximize the quality of life for people with MND and their families has been recommended by several organizations [12,19]. In recent years, there has been a significant increase in access to specialist palliative care for non-cancer patients, including those with MND [46]. Notably, community-based services have been associated with improved end-of-life outcomes for people with non-cancer conditions, including reduced hospitalizations and decreased health system costs [46]. Although the average home care costs for the population receiving CPC are higher than those not receiving CPC, overall the reduced hospital expenses outweigh the increased home care costs [44]. Community-based care is encouraged for patients suffering from progressive, life-limiting disease in Australia [47] and has contributed to the rise in people with MND accessing such services. In this study, 56.4% (738) of people with MND received their first episode of palliative care services in a community setting.

Zwicker's study also found people with MND chose to receive community palliative care approximately twice as often as people without MND in the last year of life, suggesting that this is a population willing to utilize such services to address their complex healthcare needs [45]. Mobility of these individuals can often be impaired and there is significant difficulty with transporting individuals to hospital appointments. Access to specialist palliative care and other interdisciplinary care within the community environment would reduce this barrier[48]. Moreover, community-based care supports people in their familiar surroundings, enabling continuity of care by maintaining connections with their regular healthcare providers[33]. This approach is particularly beneficial for individuals with a strong family support system, as they are more likely to remain in the community[49]. However, at present the range of resources required for comprehensive care in the community setting is still limited[45,48]. In addition, there are gaps in the community-based specialist palliative care workforce [50], and generalist palliative care providers may not fully meet the distinctive needs of people with MND[29,51,52]. More investment in palliative care teams including education about the end of life care management of people diagnosed with MND, medication access, care integration, and 24-hour home support services is required[15]. Furthermore, palliative care providers should also facilitate communication with patients and their families to clarify preferences and reduce unnecessary hospitalizations [44].

From January 1, 2013, to December 31, 2020, based on an average of two deaths from MND per day[4], approximately 5840 people are estimated to have died from MND in Australia. The number of MND deaths in the PCOC sample from this study accounts for 22.4% of the total deaths during these years. This indicates that this large-scale national study has reasonable representativeness in examining the clinical characteristics and care needs of Australian MND palliative care patients, but there are also opportunities to collect additional service-related data on this population. Our study identified associations between the clinical characteristics and utilization of different types of specialist palliative care services among people with MND using standardized and validated assessment tools. These findings have implications for other countries with comparable systems of palliative care delivery.

Limitations

This study has several limitations. Given that up to 50% of individuals with MND may have cognitive impairment [53] and/or significant difficulties with communication, assessment results of many people with MND in IPC were likely to have been reported by proxies, who are more likely to underrate patients' symptom intensity compared to family and community care providers[36], Results reported in this study should therefore be interpreted with caution. Furthermore, it is important to note that the PCOC system may not capture information on particular patient characteristics and clinical needs that may influence their utilization of different types of palliative care services. For example, decisions about treatment interventions that affect the prognosis and survival of the patient (e.g. gastrostomy feeding, ventilatory support, and use of drugs such as riluzole) may also affect the need for palliative care services but are not captured in detail by the PCOC system. Finally, people with MND may have the limited access to palliative care, some were cared for in aged care homes (given that many people dying with MND were over 65 years of age) which had limited access to palliative care services during the study period.

Conclusions

This study revealed that people with MND who had high levels of dependency and/or who were in an unstable clinical state were more likely to receive IPC as opposed to community care. People residing in aged care facilities, as well as those with lower levels of symptom distress and/or family/carers distress, were more likely to receive CPC. Most people with MND in their last stage of life had high levels of physical impairment but relatively low symptom burdens as assessed with the clinical indicators used in this study. The degree of symptom distress was not significantly associated with patients' use of inpatient versus CPC. These findings suggest that more people with MND at the last stage of life could potentially benefit from increased access to supportive services in community settings, such as skilled palliative care providers and home support for family/carers. A need-based palliative care model for people with MND may assist with developing disease-specific palliative care guidelines.

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Patient consent for publication: Not required.

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Provenance and peer review: Not commissioned; externally peer-reviewed.

Data availability statement: The research findings presented in this study are underpinned by data sourced from the Palliative Care Outcomes Collaboration (PCOC) in Australia. Access to this data is subject to certain permissions from PCOC, as it is utilized under a specific license agreement for this study. For those interested in accessing the original data supporting this study, we encourage you to directly request access to the dataset from PCOC through the following link: https://www.uow.edu.au/ahsri/pcoc/research-data/.

References

1 Warrier MG, Thomas PT, Sadasivan A, *et al.* Development of Guidelines for Spouses Engaged in Home-Based Care of Persons With Motor Neuron Disease From Indian Context. *Journal of Patient Experience*. 2022;9:237437352210775. doi: 10.1177/23743735221077535

2 National Institute for Health and Clinical Excellence (NICE). Motor neurone disease: assessment and management. 2016. nice.org.uk/guidance/ng42 (accessed 8 December 2022)

3 MND Australia. What is motor neurone disease? https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd (accessed 9 December 2022)

4 MND Australia. Motor Neurone Disease Information & Support | MND Australia. 2021. https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/overview-of-mnd-for-health-professionals (accessed 28 July 2023)

5 MND Association of South Africa. Motor Neurone Disease (MND). http://mnda.org.za/about-motor-neurone-disease-mnd/ (accessed 9 December 2022)

6 Clinical Standards Department at the Royal College of Physicians. Long-term Neurological Conditions: Management at the Interface Between Neurology, Rehabilitation and Palliative Care. 2008. https://www.rcplondon.ac.uk/guidelines-policy/long-term-neurological-conditions (accessed 13 December 2022)

7 World Health Organization. Definition of Palliative Care. 2018. https://www.who.int/cancer/palliative/definition/en/ (accessed 2 March 2023)

8 Sutton L. Addressing palliative and end-of-life care needs in neurology. *British Journal of Neuroscience Nursing*. 2008;4:235–8. doi: 10.12968/bjnn.2008.4.5.29323

9 Veronese S, Gallo G, Valle A, *et al.* Specialist palliative care improves the quality of life in advanced neurodegenerative disorders: NE-PAL, a pilot randomised controlled study. *BMJ Support Palliat Care*. 2017;7:164–72. doi: 10.1136/bmjspcare-2014-000788

10 Oliver DJ. Palliative care in motor neurone disease: where are we now? *Palliat Care*. 2019;12:1178224218813914.

11 Oliver DJ, Borasio GD, Caraceni A, *et al.* A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurol*. 2016;23:30–8. doi: 10.1111/ene.12889

12 National Institute for Health and Clinical Excellence (NICE). Motor neurone disease: assessment and management. 2016. https://www.nice.org.uk/guidance/ng42 (accessed 13 December 2022)

13 McNamara B, Rosenwax LK, Holman CDJ. A method for defining and estimating the palliative care population. *J Pain Symptom Manage*. 2006;32:5–12. doi: 10.1016/j.jpainsymman.2005.12.018

14 Nair K, Lee M, Hobson E, *et al.* End-of-life care of people with long-term neurological conditions. *PRACT NEUROL*. 2022;22:385–91.

15 Ding J, Johnson CE, Qin X, *et al.* Palliative care needs and utilisation of different specialist services in the last days of life for people with lung cancer. *Eur J Cancer Care*. 2021;30. doi: 10.1111/ecc.13331

16 Palliative Care Australia. Palliative Care Service Development Guidelines. 2018. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf (accessed 8 May 2023)

17 Whitney RL, Bell JF, Tancredi DJ, *et al.* Hospitalization Rates and Predictors of Rehospitalization Among Individuals With Advanced Cancer in the Year After Diagnosis. *J Clin Oncol*. 2017;35:3610–7. doi: 10.1200/JCO.2017.72.4963

18 Kavalieratos D, Gelfman LP, Tycon LE, *et al.* Palliative Care in Heart Failure: Rationale, Evidence, and Future Priorities. *J Am Coll Cardiol*. 2017;70:1919–30. doi: 10.1016/j.jacc.2017.08.036

19 Oliver D, Borasio GD, Johnston W, editors. *Palliative care in amyotrophic lateral sclerosis: from diagnosis to bereavement*. Third edition. Oxford: Oxford University Press 2014.

20 Palliative Care Outcomes Collaboration. Palliative Care Outcomes Collaboration Clinical Manual. 2021.

https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf (accessed 24 February 2023)

21 Daveson B, Blanchard M, Clapham S, *et al.* Population-level, patient-reported outcomes: a case study regarding a public health intervention that involves patients with life-limiting illnesses. *Front Public Health*. 2023;11:1232881. doi: 10.3389/fpubh.2023.1232881

22 University of Wollongong. Palliative care outcomes collection. https://www.uow.edu.au/ahsri/pcoc/research-data/ (accessed 8 May 2023)

23 Aoun SM, Monterosso L, Kristjanson LJ, *et al.* Measuring Symptom Distress in Palliative Care: Psychometric Properties of the Symptom Assessment Scale (SAS). *Journal of Palliative Medicine*. 2011;14:315–21. doi: 10.1089/jpm.2010.0412

24 Masso M, Allingham SF, Johnson CE, *et al.* Palliative Care Problem Severity Score: Reliability and acceptability in a national study. *Palliat Med*. 2016;30:479–85. doi: 10.1177/0269216315613904

25 Fries BE, Schneider DP, Foley WJ, *et al.* Refining a Case-Mix Measure for Nursing Homes: Resource Utilization Groups (RUG-III): *Medical Care*. 1994;32:668–85. doi: 10.1097/00005650-199407000-00002

26 Abernethy AP, Shelby-James T, Fazekas BS, *et al.* The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliat Care*. 2005;4:7. doi: 10.1186/1472-684X-4-7

27 Masso M, Allingham SF, Banfield M, *et al.* Palliative Care Phase: Inter-rater reliability and acceptability in a national study. *Palliat Med*. 2015;29:22–30. doi: 10.1177/0269216314551814

28 Australian Bureau of Statistics. SOCIO-ECONOMIC INDEXES FOR AREAS (SEIFA) 2016. 2023. https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~IRSAD~20 (accessed 27 April 2023)

29 Mc Veigh C, Donaghy C, Mc Laughlin B, *et al.* Palliative care for patients with motor neurone disease and their bereaved carers: a qualitative study. *BMC Palliat Care*. 2019;18:39.

30 Tiirola A, Korhonen T, Surakka T, *et al.* End-of-Life Care of Patients With Amyotrophic Lateral Sclerosis and Other Nonmalignant Diseases. *Am J Hosp Palliat Care*. 2017;34:154–9. doi: 10.1177/1049909115610078

31 Gibbons CJ, Thornton EW, Young CA. The patient experience of fatigue in motor neurone disease. *Front Psychol*. 2013;4:788. doi: 10.3389/fpsyg.2013.00788

32 Miller RG, Jackson CE, Kasarskis EJ, *et al.* Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review). *Neurology*. 2009;73:1218–26. doi: 10.1212/WNL.0b013e3181bc0141

33 Kamal AH, Currow DC, Ritchie CS, *et al.* Community-based palliative care: the natural evolution for palliative care delivery in the U.S. *J Pain Symptom Manage*. 2013;46:254–64. doi: 10.1016/j.jpainsymman.2012.07.018

34 Eagar K, Clapham SP, Allingham SF. Palliative care is effective: but hospital symptom outcomes superior. *BMJ Support Palliat Care*. 2020;10:186–90. doi: 10.1136/bmjspcare-2018-001534

35 Clark K, Connolly A, Clapham S, *et al.* Physical Symptoms at the Time of Dying Was Diagnosed: A Consecutive Cohort Study To Describe the Prevalence and Intensity of Problems Experienced by Imminently Dying Palliative Care Patients by Diagnosis and Place of Care. *J Palliat Med*. 2016;19:1288–95. doi: 10.1089/jpm.2016.0219

36 de Graaf E, Zweers D, de Graeff A, *et al.* Symptom Intensity of Hospice Patients: A Longitudinal Analysis of Concordance Between Patients' and Nurses' Outcomes. *J Pain Symptom Manage*. 2018;55:272–81. doi: 10.1016/j.jpainsymman.2017.09.005

37 Aoun SM, Deas K, Kristjanson LJ, *et al.* Identifying and addressing the support needs of family caregivers of people with motor neurone disease using the Carer Support Needs Assessment Tool. *Palliat Support Care*. 2017;15:32–43. doi: 10.1017/S1478951516000341

38 Watermeyer TJ, Brown RG, Sidle KCL, *et al.* Impact of disease, cognitive and behavioural factors on caregiver outcome in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*. 2015;16:316–23. doi: 10.3109/21678421.2015.1051990

39 Cheng HWB, Chan OMI, Chan CHR, *et al.* End-of-life Characteristics and Palliative Care Provision for Patients With Motor Neuron Disease. *Am J Hosp Palliat Care*. 2018;35:847–51. doi: 10.1177/1049909117735832

40 Seow H, Barbera L, Sutradhar R, *et al.* Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. *J Clin Oncol*. 2011;29:1151–8. doi: 10.1200/JCO.2010.30.7173

41 Gwilliam B, Keeley V, Todd C, *et al.* Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ*. 2011;343:d4920. doi: 10.1136/bmj.d4920

42 Ding J, Cook A, Qin X, *et al.* 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. doi: 10.1016/j.ijnurstu.2020.103655

43 Lerum SV, Solbraekke KN, Frich JC. Healthcare professionals' accounts of challenges in managing motor neurone disease in primary healthcare: a qualitative study. *Health Soc Care Community*. 2017;25:1355–63. doi: 10.1111/hsc.12432

44 Warrier MG, Thomas PT, Sadasivan A, *et al.* Family Caregivers' Experiences with Dying and Bereavement of Individuals with Motor Neuron Disease in India. *J SOC WORK END-LIFE*. 2019;15:111–25.

45 Zwicker J, Qureshi D, Talarico R, *et al.* Dying of amyotrophic lateral sclerosis: Health care use and cost in the last year of life. *Neurology*. 2019;93:e2083–93. doi: 10.1212/WNL.0000000000008582

46 Rosenwax L, Spilsbury K, McNamara BA, *et al.* A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? *BMC Palliat Care*. 2016;15:46.

47 Youens D, Moorin R. The Impact of 1on Utilization and Cost of Acute Care Hospital Services in the Last Year of Life. *Journal of Palliative Medicine*. 2017;20:736–44. doi: 10.1089/jpm.2016.0417

48 Olvera CE, Levin ME, Fleisher JE. Community-based neuropalliative care. *Handb Clin Neurol*. 2023;191:49–66. doi: 10.1016/B978-0-12-824535-4.00001-X

49 Collis E, Al-Qurainy R. Care of the dying patient in the community. *BMJ*. 2013;347:f4085. doi: 10.1136/bmj.f4085

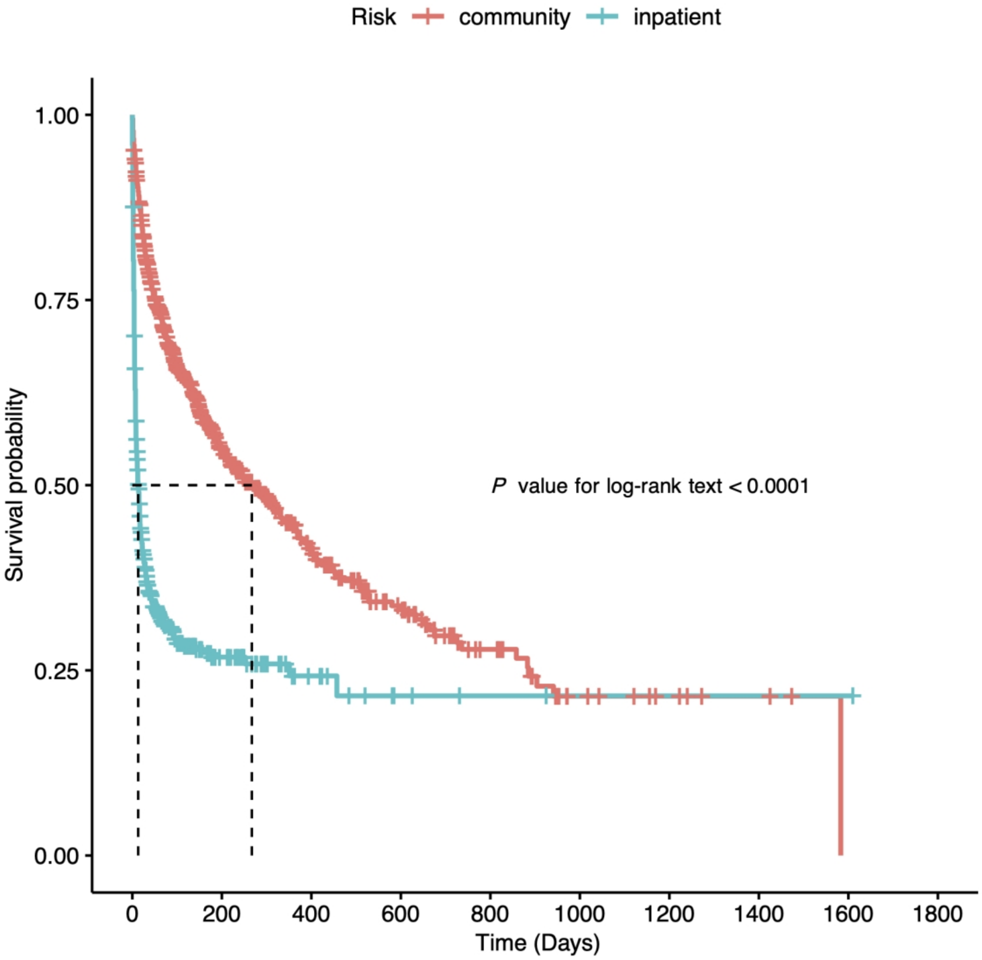
50 Australian Institute of Health and Welfare. Palliative care services in Australia, Palliative care workforce - Australian Institute of Health and Welfare. 2023. https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce (accessed 3 July 2023)

51 Brewah H, Borrett K, Tavares N, *et al.* Perceptions of people with motor neurone disease, families and HSCPs: a literature review. *Br J Community Nurs*. 2022;27:188–98.

52 Bentley B, O'Connor M. The End-of-Life Experiences of People with Motor Neuron Disease: Family Carers' Perspectives. *J PALLIAT MED*. 2016;19:857–62.

53 Miller RG, Jackson CE, Kasarskis EJ, *et al.* Practice Parameter update: The care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2009;73:1227–33. doi: 10.1212/WNL.0b013e3181bc01a4

Figure 1: Survival curves for MND patients in inpatient versus community palliative care. Time (in days) is shown on the x-axis, and Survival Probability is shown on the y-axis. The log-rank test was used to compare the survival curves between the two groups. Notably, inpatients had a much shorter time interval between palliative care admission and death compared to the community care group (P < 0.0001).



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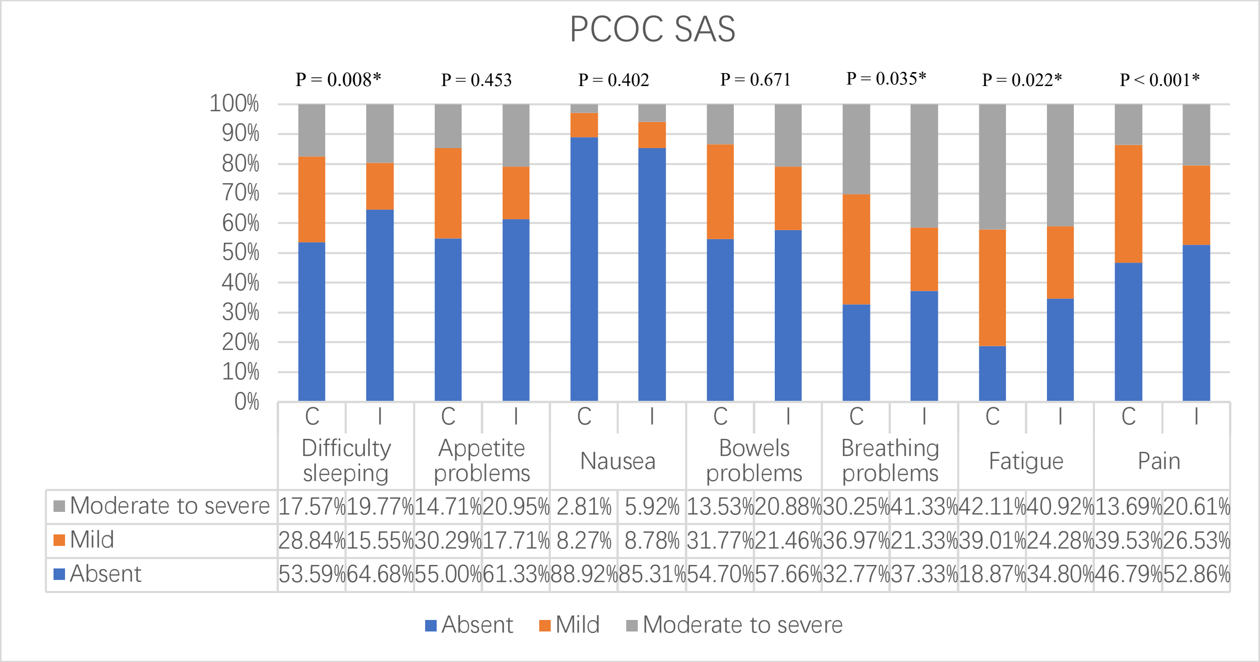
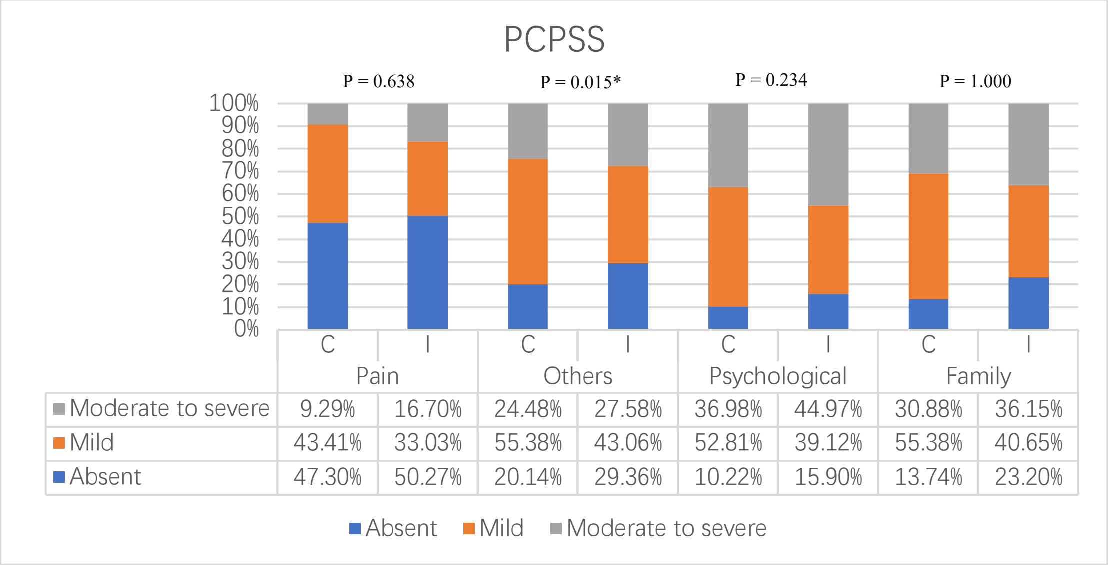
152x152mm (300 x 300 DPI)



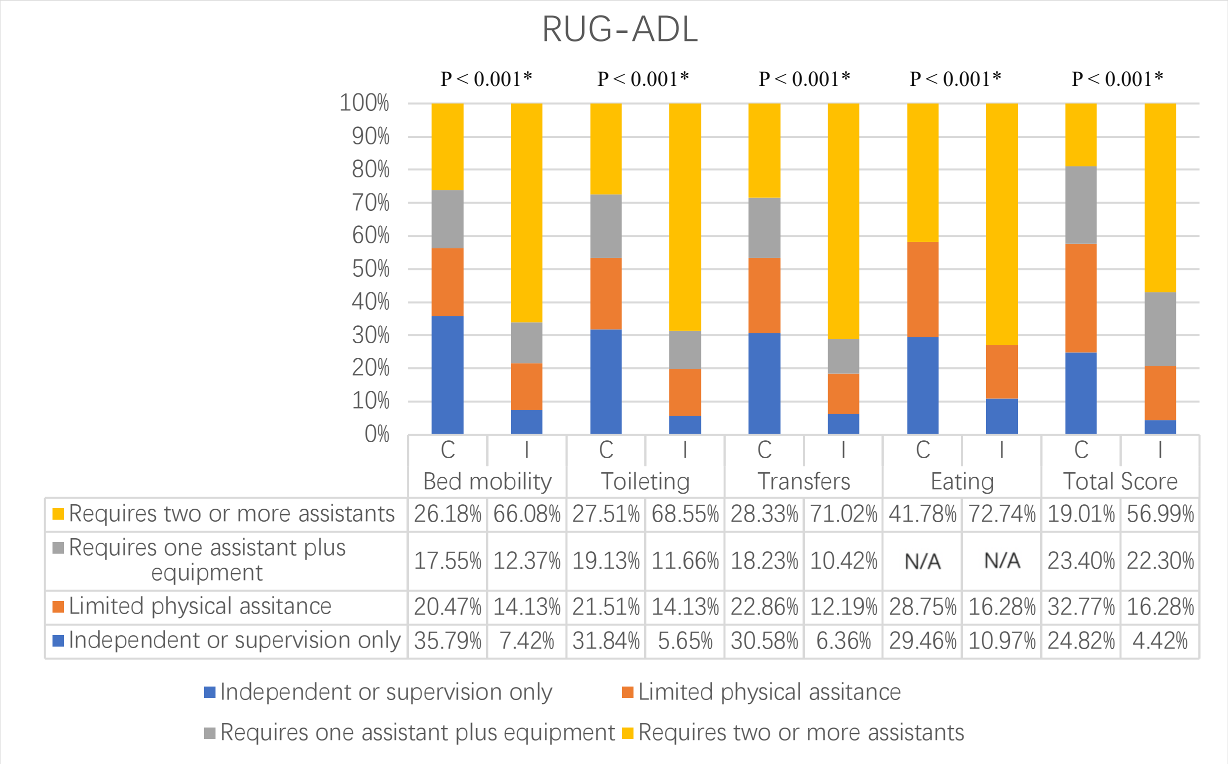
	Difficulty sleeping		Appetite problems		Nausea		Bowels problems		Breathing problems		Fatigue		Pain	
	C	I	C	I	C	I	C	I	C	I	C	I	C	I
■ Moderate to severe	17.57%	19.77%	14.71%	20.95%	2.81%	5.92%	13.53%	20.88%	30.25%	41.33%	42.11%	40.92%	13.69%	20.61%
■ Mild	28.84%	15.55%	30.29%	17.71%	8.27%	8.78%	31.77%	21.46%	36.97%	21.33%	39.01%	24.28%	39.53%	26.53%
■ Absent	53.59%	64.68%	55.00%	61.33%	88.92%	85.31%	54.70%	57.66%	32.77%	37.33%	18.87%	34.80%	46.79%	52.86%

Figure S1. *Distribution for levels of distress associated with patient-reported SAS symptoms*



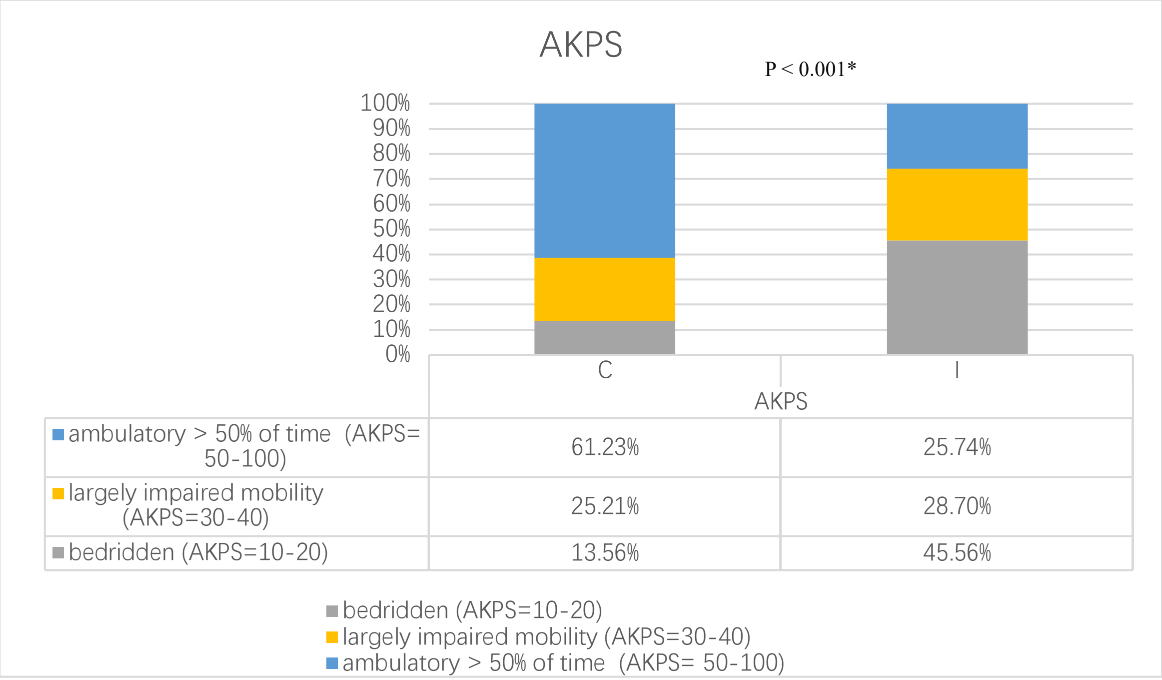
	Pain		Others		Psychological		Family	
	C	I	C	I	C	I	C	I
■ Moderate to severe	9.29%	16.70%	24.48%	27.58%	36.98%	44.97%	30.88%	36.15%
■ Mild	43.41%	33.03%	55.38%	43.06%	52.81%	39.12%	55.38%	40.65%
■ Absent	47.30%	50.27%	20.14%	29.36%	10.22%	15.90%	13.74%	23.20%

Figure S2. *Distribution for levels of clinician-rated palliative care problems*



	Bed mobility C	Bed mobility I	Toileting C	Toileting I	Transfers C	Transfers I	Eating C	Eating I	Total Score C	Total Score I
🟨 Requires two or more assistants	26.18%	66.08%	27.51%	68.55%	28.33%	71.02%	41.78%	72.74%	19.01%	56.99%
⬜ Requires one assistant plus equipment	17.55%	12.37%	19.13%	11.66%	18.23%	10.42%	N/A	N/A	23.40%	22.30%
🟧 Limited physical assitance	20.47%	14.13%	21.51%	14.13%	22.86%	12.19%	28.75%	16.28%	32.77%	16.28%
🟦 Independent or supervision only	35.79%	7.42%	31.84%	5.65%	30.58%	6.36%	29.46%	10.97%	24.82%	4.42%

Figure S3. *Distribution for levels of clinician-rated level of dependency*



	AKPS C	AKPS I
🟦 ambulatory > 50% of time (AKPS= 50-100)	61.23%	25.74%
🟨 largely impaired mobility (AKPS=30-40)	25.21%	28.70%
⬜ bedridden (AKPS=10-20)	13.56%	45.56%

Figure S4. *Distribution for levels of clinician-rated performance status*

For figures S1-4:

Abbreviations: C: Community patients; I: Inpatients

*NOTE. * indicates significant value p < 0.05.*

Comparisons of distributions between community patients and inpatients were performed using Pearson’s Chi-square test

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	**Item #**	**Recommendation**	**Reported on page #**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3,4
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4,5
Bias	9	Describe any efforts to address potential sources of bias	12,13
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5,6
		(*b*) Describe any methods used to examine subgroups and interactions	Not applicable
		(*c*) Explain how missing data were addressed	7
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	4
		(*e*) Describe any sensitivity analyses	Not applicable
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	4
		(b) Give reasons for non-participation at each stage	Not applicable
		(c) Consider use of a flow diagram	Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	6,7
		(b) Indicate number of participants with missing data for each variable of interest	6,7
Outcome data	15*	Report numbers of outcome events or summary measures	6-10
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	9,10
		(*b*) Report category boundaries when continuous variables were categorized	6,7
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Not applicable
Discussion			
Key results	18	Summarise key results with reference to study objectives	10-12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	13

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.