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Palliative care needs and utilisation of specialist services for people diagnosed with motor neuron 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 neuron disease (MND). However, the palliative care needs of this population and the utilisation of different specialist services remain poorly defined.

Objectives To (1) describe clinical characteristics, symptom burden and functional levels of patients dying with MND on their admission to palliative care services; (2) 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.

Participants A total of 1308 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 patients with MND 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' (OR=11.53, 95% CI: 4.87 to 27.26) and those in 'unstable' relative to 'stable' palliative care phases (OR=16.74, 95% CI: 7.73 to 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.

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 neuron disease in the palliative phase could potentially have been cared for in a community setting if greater access to supportive services were available.
- ⇒ The Palliative Care Outcomes Collaboration data may not fully capture information on particular patient characteristics and clinical needs that may influence their utilisation of different types of palliative care services.

INTRODUCTION

Motor neuron 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 2100 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 2 to 5 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—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, dyspnoea, 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 optimise palliative care for people with MND by providing the 'right care in the right place at the right time'.

Palliative care in Australia is recognised 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 the 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 with inpatient options, CPC significantly improves symptom management and quality of life while reducing healthcare utilisation 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 utilisation 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 (1) describe the symptom burden and level of function of people with MND on their first admission to IPC and CPC before death, and (2) determine factors associated with receiving inpatient or CPC 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 programme focused on improving the quality and outcomes in palliative care. The PCOC programme, 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 (14.8–25.1%). In 2012, the national initiative reported 16 358 deaths, which increased to 32 421 deaths in 2022.[21] The Palliative Care Outcomes Collaboration's data set collects demographic, setting and clinical assessment information for palliative care patients and now comprises data describing more than 250 000 patients.[22] IPC services conduct detailed assessments of individual patients on admission and then at least daily and at phase change. CPC services perform assessments on admission and during each subsequent encounter (eg, 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 analysed, the PCOC programme conducts a review and data cleaning process. Participating services receive 6 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: (1) required specialist palliative care from one or more of the services across Australia registered in PCOC; (2) required palliative care principally for MND; (3) with a first episode of care occurring between 1 January 2013 and 31 December 2020; and (4) 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 (ie, 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 (ie, 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, 4-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 3-point item (1–independent or supervision only; 3–total dependence/tube fed), and the other three activities (toileting, bed mobility and transfers) with 5-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 socioeconomic 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 (SD) and medians (with IQR). Differences between the two types of specialist palliative care episodes (community and inpatient) were assessed using Pearson's χ^2 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 CPC services. Factors significantly associated with the utilisation of different specialist services were determined by using stepwise procedures. Multicollinearity was assessed using variance inflation factors. In our multivariate models, inclusion and exclusion criteria were set at significance levels of 0.05 and 0.10, respectively. We also used 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: (1) 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); (2) PCPSS was classified as follows: for PCPSS: 0=absent (corresponding to PCPSS=0), 1=mild (PCPSS=1), 2=moderate-to-severe (PCPSS=2–3); (3) 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); (4) 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 V.26.0. The C-index and Kaplan-Meier curves were estimated using R statistical software V.4.0. P values<0.05 were considered statistically significant.

RESULTS

Study population

A total of 1308 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 men, 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 socio-demographic characteristics. The specific socio-demographic and clinical characteristics of people with MND are shown in table 1.

Episode of care characteristics

On average, inpatients had a much shorter interval between palliative care admission and death compared with the individuals in the community care group (31 days vs 249 days; p<0.0001) (figure 1). Compared with 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

Table 1 Baseline socio-demographic and clinical characteristics for people with motor neuron disease by episode settings

Characteristics of patients	All N (%)	Community N (%)	Inpatient N (%)	P values for differences by setting
Socio-demographic 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				

Continued

Table 1 Continued

Characteristics of patients	All N (%)	Community N (%)	Inpatient N (%)	P values for differences by setting
≤1 week	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 months	254 (19.4)	161 (21.8)	93 (16.3)	
3 months~6 months	192 (14.7)	141 (19.1)	51 (9.0)	
>6 months	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)	

Comparisons between the two groups were conducted using Pearson's χ^2 tests. Missing data entries were not accounted for in the analyses.
*Indicates significant value p<0.05.
N/A, Not applicable.SEIFA, Socio-Economic Indexes for Areas;

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 with 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 a 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.

Factors associated with the utilisation 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 vs private residences (OR=0.24; 95% CI: 0.12 to 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 with those in the 'stable' phase, people with MND in an 'unstable' phase had increased odds for utilisation of IPC versus CPC (OR=16.74; 95% CI: 7.73 to 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 utilisation. 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 to 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).

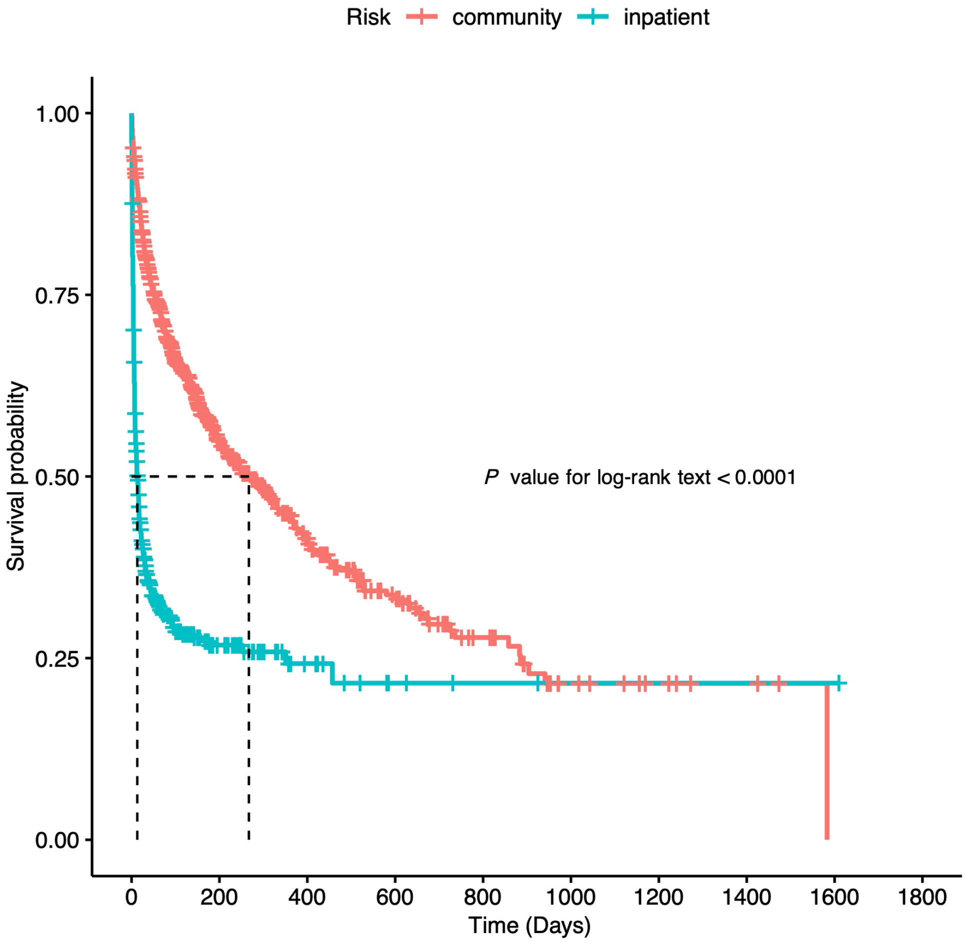

Figure 1 Survival curves for patients with motor neuron disease in inpatient versus community palliative care. Time (in days) is shown on the x-axis, and survival probability is shown on the y-axis. The log-rank test was used to compare the survival curves between the two groups. Notably, inpatients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

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 CPC 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 utilisation 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 categorised as 'absent' or 'mild' (online supplemental figures S1 and 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 patients with lung cancer conducted by Ding *et al*.[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 the 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 patients and CPC providers[15] in the

Table 2 Clinical outcome measures for patients with motor neuron disease 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	1.22 (0.81) 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*

Comparisons between the two groups were conducted using the Mann-Whitney U test.
*Indicates significant value p<0.05.
AKPS, Australian-modified Karnofsky Performances Status; PCPSS, Palliative Care Problem Severity Score; RUG-ADL, Resource Utilisation Group-Activities for Daily Living; PCOC SAS, Symptom Assessment Scale.

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 on 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 emphasised 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

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

	Inpatient vs community unadjusted OR (95% CI, p value)*	Inpatient vs community adjusted OR (95% CI, p value)†	P for trend
Characteristics of patients and episodes of care			
Age groups (Ref. <65 years)			
65–75 years	1.13 (0.87 to 1.46; 0.37)	1.50 (0.89 to 2.53; 0.13)	0.734
>75 years	1.04 (0.79 to 1.37;0.77)	0.90 (0.52 to 1.56; 0.72)	
Sex (Ref. male)	1.21 (0.97 to 1.51; 0.09)	1.13 (0.74 to 1.73; 0.59)	
Admission of year (Ref. 2013)			
2014	0.97 (0.59 to 1.59; 0.89)	1.04 (0.42 to 2.60; 0.93)	0.050‡
2015	0.87 (0.54 to 1.39; 0.55)	0.43 (0.17 to 1.09; 0.08)	
2016	0.85 (0.54 to 1.33; 0.47)	0.36 (0.15 to 0.86; 0.02‡)	
2017	0.61 (0.39 to 0.97; 0.04‡)	0.33 (0.13 to 0.83; 0.02‡)	
2018	0.76 (0.49 to 1.20; 0.24)	0.41 (0.17 to 0.97; 0.04‡)	
2019	0.61 (0.39 to 0.96; 0.03‡)	0.38 (0.16 to 0.93; 0.03‡)	
2020	0.87 (0.53 to 1.40; 0.56)	0.41 (0.16 to 1.03; 0.06)	
Referral source (Ref. hospital)			
Community service	0.67 (0.52 to 0.86; 0.001‡)	1.32 (0.84 to 2.07; 0.23)	
Others	0.13 (0.07 to 0.24; <0.001‡)	0.32 (0.09 to 1.22; 0.10)	
Episode start accommodation (Ref. private residence)			
Residential aged care	0.54 (0.35 to 0.82; 0.004‡)	0.24 (0.12 to 0.49; <0.001‡)	
Other	0.94 (0.47 to 1.85; 0.85)	1.32 (0.35 to 4.95; 0.68)	
Days until death (Ref. ≤1 week)			
1 week~1 month	0.27 (0.18 to 0.40; <0.001‡)	0.18 (0.09 to 0.34; <0.001‡)	<0.001‡
1 month~3 months	0.13 (0.09 to 0.19; <0.001‡)	0.08 (0.04 to 0.16; <0.001‡)	
3 months~6 months	0.08 (0.05 to 0.13; <0.001‡)	0.07 (0.03 to 0.15; <0.001‡)	
>6 months	0.04 (0.03 to 0.06; <0.001‡)	0.02 (0.01 to 0.04; <0.001‡)	
Clinical measures			
Phase type (Ref. stable)			
Unstable	29.65 (18.55 to 47.39; <0.001‡)	16.74 (7.73 to 36.24; <0.001‡)	
Deteriorating	1.65 (1.23 to 2.20; 0.001‡)	0.68 (0.40 to 1.15; 0.15)	
Terminal	13.95 (7.43 to 26.17; <0.001‡)	0.70 (0.23 to 2.07; 0.52)	
SAS appetite (Ref. absent)			
Mild	0.53 (0.39 to 0.70; <0.001‡)	0.86 (0.50 to 1.46; 0.57)	0.983
Moderate/severe	1.28 (0.94 to 1.74; 0.12)	1.78 (0.99 to 3.22; 0.06)	
PCPSS-pain (Ref. absent)			
Mild	0.72 (0.56 to 0.91; 0.007‡)	0.58 (0.37 to 0.93; 0.03‡)	0.258
Moderate/severe	1.69 (1.19 to 2.40; 0.003‡)	0.78 (0.39 to 1.57; 0.49)	
PCPSS-family (Ref. absent)			
Mild	0.44 (0.32 to 0.59; <0.001‡)	0.36 (0.20 to 0.64; 0.001‡)	0.290
Moderate/severe	0.69 (0.50 to 0.96; 0.03‡)	0.35 (0.18 to 0.67; 0.002‡)	
PCPSS-other symptoms (Ref. absent)			
Mild	0.48 (0.33 to 0.68; <0.001‡)	1.07 (0.54 to 2.12; 0.84)	0.550
Moderate/severe	0.78 (0.55 to 1.12; 0.18)	0.60 (0.29 to 1.24; 0.17)	
RUG-ADL total (Ref. independent)			
Limited physical assistance	2.79 (1.72 to 4.52; <0.001‡)	2.23 (0.98 to 5.19 0.06)	<0.001‡

Continued

Table 3 Continued

	Inpatient vs community unadjusted OR (95% CI, p value)*	Inpatient vs community adjusted OR (95% CI, p value)†	P for trend
Requires one assistant plus equipment	5.35 (3.31 to 8.63; <0.001‡)	3.65 (1.54 to 8.65; 0.003‡)	
Requires two assistants for full care	16.82 (10.57 to 26.78; <0.001‡)	11.53 (4.87 to 27.26; <0.001‡)	

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.

*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.

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

‡Indicates significant value p<0.05.

AKPS, Australian-modified Karnofsky Performances Status; PCOC, Palliative Care Outcomes Collaboration; PCPSS, Palliative Care Problem Severity Score; Ref., reference; RUG-ADL, Resource Utilisation Group-Activities for Daily Living; SAS, Symptoms Assessment Scale.

RUG-ADL total scores >13), whereas those admitted to CPC typically needed more limited assistance (online supplemental figure S3). The AKPS results suggest that around 39% of individuals receiving community care experienced impairment in mobility, compared with 74% of inpatients (online supplemental figure S4). Additionally, inpatients had a much shorter time between palliative care admission and death compared with 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 use inpatient services compared with 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 specialised 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 maximise the quality of life for people with MND and their families has been recommended by several organisations.[12 19] In recent years, there has been a significant increase in access to specialist palliative care for patients without cancer, 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 hospitalisations 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 diseases 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 CPC approximately twice as often as people without MND in the last year of life, suggesting that this is a population willing to use 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 hospitalisations.[44]

From 1 January 2013 to 31 December 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 utilisation of different types of specialist palliative care services among people with MND using standardised 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 under-rate patients' symptom intensity compared with 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 utilisation of different types of palliative care services. For example, decisions about treatment interventions that affect the prognosis and survival of the patient (eg, 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 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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