Author/s:
Disler, R;Pascoe, A;Chen, XE;Lawson, E;Cahyadi, M;Paalendra, A;Hickson, H;Wright, J;Phillips, B;Subramaniam, S;Glenister, K;Philip, J;Donesky, D;Smallwood, N

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Original Article

Palliative Approach Remains Lacking in Terminal Hospital Admissions for Chronic Disease Across Rural Settings: Multisite Retrospective Medical Record Audit

Rebecca Disler, PhD, Amy Pascoe, PhD, Xinye Esther Chen, MD, Emily Lawson, MD, Michael Cahyadi, MD, Ajanth Paalendra, MD, Helen Hickson, PhD, Julian Wright, PhD, Bronwyn Phillips, PhD, Sivakumar Subramaniam, PhD, Kristen Glenister, PhD, Jennifer Philip, PhD, Doranne Donesky, PhD, and Natasha Smallwood, PhD

Respiratory Research@Alfred, Department of Immunology and Pathology (R.D., A.Y.P., N.S.), Central Clinical School, Monash University, Melbourne, Australia; Department of Rural Health (R.D., E.L., H.H., J.W., S.S., K.G.), The University of Melbourne, Shepparton, VIC, Australia; Eastern Health (X.E.C.), Melbourne, VIC, Australia; Monash Rural School (M.C., A.P.), Mildura, VIC, Australia; Goulburn Valley Health (J.W., S.S.), Shepparton, VIC, Australia; Murray Primary Health Network (B.P.), Bendigo, VIC, Australia; The University of Melbourne (J.P.), Parkville, VIC, Australia; Department of Physiological Nursing (D.D.), University of California San Francisco, San Francisco, USA; Department of Respiratory and Sleep Medicine (N.S.), The Alfred Hospital, Melbourne, Australia

Abstract

Introduction/Aim. Despite clear benefit from palliative care in end-stage chronic diseases, access is often limited, and rural access largely undescribed. This study sought to determine if a palliative approach is provided to people with chronic disease in their terminal hospital admission.

Methods. Multisite, retrospective medical record audit, of decedents with a primary diagnosis of chronic lung, heart, or renal failure, or multimorbidity of these conditions over 2019.

Results. Of 241 decedents, across five clinical sites, 143 (59.3%) were men, with mean age 80.47 years (SD 11.509), and diagnoses of chronic lung (n = 56, 23.2%), heart (n = 56, 23.2%), renal (n = 24, 10.0%) or multimorbidity disease (n = 105, 43.6%), and had 2.88 (3.04SD) admissions within 12 months. Outpatient chronic disease care was evident (n = 171, 73.7%), however, contact with a private physician (n = 91, 37.8%), chronic disease program (n = 61, 25.3%), or specialist nurse (n = 17, 7.1%) were less apparent. "*Not-for-resuscitation*" orders were common (n = 139, 57.7%), however, advance care planning (n = 71, 29.5%), preferred place of death (n = 18, 7.9%), and spiritual support (n = 18, 7.5%) were rarely documented. Referral to and input from palliative services were low (n = 74, 30.7% and n = 49, 20.3%), as was review of nonessential medications or blood tests (n = 86, 35.7%, and n = 78, 32.4%). Opioids were prescribed in 45.2% (n = 109). Hospital site and diagnosis were significantly associated with outpatient care and palliative approach ($P<0.001$).

Conclusions. End-of-life planning and specialist palliative care involvement occurred infrequently for people with chronic disease who died in rural hospitals. Targeted strategies are necessary to improve care for these prevalent and high needs rural populations. J Pain Symptom Manage 2024;67:453−462. *© 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)*

Key Words

Palliative care, Rural, Chronic disease

Introduction

Chronic diseases are the leading cause of death and disability, accounting for 74% of global deaths.[1] One third of Australian deaths are due to two groups of chronic conditions: cardiovascular and respiratory disease which account for high health expenditure

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Address correspondence to: Rebecca Disler, Respiratory Research, Department of Immunology & Pathology, Central Clinical School, Level 4 The Alfred Centre, 99 Commercial Road, Melbourne 3004, Australia. E-mail: rebecca.disler@monash.edu

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(>676,000 hospitalizations, $12.7bn of health budget, 2020-21 data),[2,3] create marked physical, psychological, and socio-economic burden,[4–6] particularly in the last year of life.[7] The World Health Organization recommends that it is a global ethical responsibility to relieve health-related suffering by integrating palliative care into health services,[8] yet, of the 40 million people worldwide who need palliative care, only 14% receive it.[9]

Access to palliative care in chronic disease is of particular concern,[4,6] with global and local data indicating that less than 7% of people with cardiovascular and chronic respiratory disease are referred to specialist palliative care prior to, and less than half during terminal admissions,[10–13] and these diseases representing under 4% of all palliative care referrals.[11] Palliative care is similarly under-utilized in end-stage kidney disease, or renal failure, despite evidence that early palliative care intervention can improve outcomes amongst this group whom often have intensive medical input towards end of life.[14]

The incidence and burden of chronic diseases are often greater in rural and regional areas compared with metropolitan areas, owing in part to social disadvantage and increased prevalence of risk factors such as smoking, alcohol consumption, and obesity.[15] Despite this, access to end-of-life care decreased with increasing remoteness and geographical inequities.[16] Internationally, access to palliative care remains limited; in rural America for example 90% of hospitals with palliative care are situated in urban areas and only 17% of rural hospitals with fifty or more beds report palliative care programs.[16] In Australia, a shortage of specialists is exacerbated by vast geography, further hindering accessibility to palliative care services for rural and regional patients.[17]

A retrospective medical record audit of a major, regional hospital in Australia revealed that of the patients who died from 2004 to 2015 from chronic respiratory disease, only 2.5% had a palliative care referral made during a past admission and only 3.3% had palliation documented as the goal of care prior to their terminal admission.[18] In 2020, 72% of Australian palliative care nurses were primarily employed in major cities.[19] Australian palliative medicine physicians are similarly sparse, with 1.2 full-time equivalent palliative care physicians per 100,000 population in major cities, compared to 0.8 and 0.5 in inner and outer regional areas respectively.[19] Palliative care staff availability in areas classified as 'remote' or 'very remote' were too low to even warrant inclusion in reports.[19] Despite government recommendations for palliative care services to be accessible for all, there remains a lack of specialized and culturally appropriate services in regional and remote areas of Australia. The necessity to relocate for services is in contrast with this population's reported preference to die at home, connected to land, and family adds further complexity to the situation.[15]

To date, there have been many missed opportunities to improve access and coordination of rural Australian palliative care services, with existing approaches remaining primarily focused on malignant disease. A recent study looking at services-level characteristics in 42 rural Australian health services revealed varied models of care delivery and limited involvement with chronic disease.[20] There is an urgent need to better understand existing care patterns for people living with non-malignant chronic disease in rural and regional areas and examine how these may influence access to palliative care approaches. Therefore, this study aimed to examine the characteristics and palliative care utilization of decedents with end-stage chronic disease in regional and rural areas in Australia,[21] to better understand how future services can be developed to better support care for this population.

Methods

Aims

This study aimed to examine patient and care characteristics, as well as palliative care provisions prior to and during terminal admission, for decedents with chronic disease in the rural and regional areas of the Australian state of Victoria, the countries second most populace state with a rural and regional dwelling population of 1.55 million, through audit of five health services.

Design Participants and Setting

Five identified health services were asked to retrieve files for people who had died over 12 months (2019 calendar year) with a primary diagnosis of chronic obstructive pulmonary disease (COPD), chronic cardiac failure (CCF), or end-stage renal failure (ESRF) over 2019, as classified under the International Classification of Disease (ICD-10) codes for: COPD: J43-44, CCF: I50, I11.0 and J81, and ESRF: N18.9, N19. Multimorbidity was defined as decedents who were coded with multiple primary diagnoses of interest.

Study Sites

Five large rural and regional health services were selected for this study to reflect variations in service characteristics across the catchment. The overall region covers a service population of 644,000, over 100,000 km^2. Services included: 1) Bendigo Health – a major, regional health service with a catchment area covering a quarter of the size of the state (catchment population: 269,000). A community palliative care service is available, as well as consultant led in-patient palliative care, and a hospice and evaluation unit comprising of ten hospice beds and eight geriatric evaluation and management beds to provide specialist palliative care to patients. 2) Mildura Base Hospital is a tertiary teaching hospital geographically located in the far North West of the state, with a palliative care and rehabilitation unit and community-based, nurse-led specialist palliative care service (catchment population: 80,000). 3) Swan Hill District Health offer fully integrated public health services that deliver specialist community palliative care in collaboration with local community and general practitioner services (catchment population: 29,000). And 4) Castlemaine Health and 5) Echuca Regional Health offer a range of hospital and healthcare services including generalist palliative care services integrated within usual care (catchment population: 20,000 and 12,000 respectively).

Ethics

This retrospective audit was approved and conducted in accordance with Bendigo Health Human Research Ethics Committee (HREC: LNR/19/BHCG/51009) as the overseeing HREC, with individual research governance clearance approved by the five sites.

Data Collection

Deidentified data were collected, including 1) demographic and medical history characteristics: age, sex, health service, age-adjusted Charlson Comorbidity Index 10-year survival probability (CCI),[22] number of admissions in past year, number of emergency department presentation in past year, living arrangements, and private health insurance cover; 2) terminal admission characteristics: length of stay, admitting team, and referring team; 3) outpatient care involvement: outpatient care teams, and provision of symptom education support; 4) indicators of palliative care: referral to palliative care, previous palliative care involvement, documented advance care planning (ACP) discussions, documented not-for-resuscitation (NFR) orders, documented preferred place of death, documented actual place of death; and 5) end-of-life care provisions: opioid usage, pressure area management, dyspnoea (also called breathlessness) management, respiratory supports, pain management, secretion management, review of nonessential medications, review of requirement for routine blood tests, nausea management, nutrition supports, and spiritual care.

Data Analysis

Results are presented descriptively by the primary diagnosis subgroups with descriptive statistics (mean and standard deviation unless stated otherwise). Exploratory analyses of independent factor effects on: 1) palliative care referral; 2) previous palliative care input; 3) documented completion of NFR orders; 4) documented completion of ACP; 5) review of nonessential medications; and 6) review and cessation of routine blood tests, were conducted using one-way ANOVAs or Kruskal-Wallis test for nonparametric data. Independent factors included in the analysis were: sex; age; CCI; primary diagnosis; location of terminal admission; living arrangements (alone vs living with others); admitting team; specialist outpatient contact; palliative care referral; previous input from a palliative care team (community or in patient); prior completion of NFR status; prior completion of ACP; documented preferred place of death; actual place of death; opioid use; review of nonessential medications; review +/- cessation of routine blood tests; symptom management education; and length of stay. Results of one-way ANOVAs are presented as *P* values. A Bonferroni correction for multiple comparisons was applied with an adjusted significance set at 0.003 (initial alpha 0.05, 18 comparisons).

Results

Demographics and Medical History

Two hundred and forty-one decedents were identified (Table 1). Half of the identified deaths were at Bendigo Health (n = 119, 49.4%), 48 at Mildura (19.9%), 27 at Echuca (11.2%), 25 at Castlemaine (10.4%) and 22 at Swan Hill (9.1%). Across all sites, decedents had an overall mean age of 80.5 years and slight male predominance (n = 143, 59.3%). CCF and COPD were the most common singular diagnoses (n = 56, 23.2% for each condition), however nearly half of decedents (n = 105, 43.6%) had some combination of multimorbidity of the eligible conditions. Mean age-adjusted 10-year survival probability as calculated using the CCI was 1.88% (SD 10.003). Mean age-adjusted 10-year survival was considerably higher amongst decedents with COPD-only (mean 7.19%, SD 19.756) as compared to decedents with CCF-only (mean 0.44%, SD 0.792), ESRF-only (mean 0.00%, SD 0.000), or multimorbidity (mean 0.28%, SD 2.560).

The overall mean for both number of admissions and emergency department (ED) presentations related to a chronic condition in the year prior to death was 2.8 (SD 3.04) and 2.6 (SD 4.64) respectively, with a higher average number of admissions for decedents with COPD only (3.4, SD = 8.02) and CCF only (2.6, SD = 3.95). Amongst the 236 decedents with documented living conditions, nearly half lived with family and friends (n = 99, 41.9%) and a third lived in an aged care facility (n = 72, 30.5%). The remainder lived alone, either with (n = 37, 15.7%) or without support, such as a live-in career or family member who provides informal care (n = 28, 11.9%). Fewer than one quarter

Table 1

Demographic and Medical History Characteristics

Characteristics	Total (n = 241)		COPD (n = 56)		CCF (n = 56)		ESRF (n = 24)		Multiple conditions (n=105)	
	n	%	n	%	n	%	n	%	n	%
Male	143	59.3	39	69.6	26	46.4	14	58.3	64	59.3
	Mean (SD)	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**
Age	80.47 (11.509)	26 - 102	75.38 (13.315)	26-96	82.96 (11.592)	47-101	79.83 (10.184)	54-95	82.04 (9.904)	26-102
Location of terminal admission	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
- Bendigo	119	49.9	37	66.1	37	50.0	7	29.2	47	44.8
- Mildura	48	19.9	6	10.7	5	8.9	11	45.8	26	24.8
- Echuca	27	11.2	6	10.7	7	12.5	2	8.3	12	11.4
- Castlemaine	25	10.4	2	3.6	7	12.5	1	4.2	15	14.3
- Swan Hill	22	9.1	5	8.9	9	16.1	3	12.5	5	4.8
	Mean (SD)	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**
Charleston Comorbidity Index Z-Score (10 year survival probability)	1.88 (10.003)	0.00 −95.03	7.19 (19.756)	0.00 − 95.03	0.44 (0.792)	0.00 − 1.85	0.00 (0.000)	0.00 − 0.00	0.28 (2.560)	0.00 − 26.14
Number of Admissions in past 1 year	2.80 (3.040)	0 − 18	3.07(3.389)	0-14	3.07(3.577)	0-18	1.67(2.078)	0-9	2.77(2.676)	0-16
Number of ED Presentations related to a chronic condition in past 1 year	2.57 (4.636)	0 - 59	3.36(8.015)	0-59	2.638(3.946)	0-23	1.46(1.587)	0-5	2.35(2.484)	0-16
Living Arrangement (n = 236)	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
- alone without supports	28	11.9	8	14.8	5	9.4	5	20.8	10	9.5
- alone with supports	37	15.7	4	7.4	9	17.0	4	16.7	20	19.0
- with family or friends	99	41.9	28	51.9	20	37.7	9	37.5	42	40.0
- in an aged care facility	72	30.5	14	25.9	19	35.8	6	25.0	33	31.4
Private healthcare insurance coverage	n=235		n=54		n=53		n=23		n=105	
- Yes	52	22.1	45	83.3	38	71.7	19	82.6	81	77.1
- No	183	77.9	9	16.7	15	28.3	4	17.4	24	22.9

Table 2
Terminal Admission

Inpatient care of terminal admission	Total (n = 241)		COPD (n = 56)		CCF (n = 56)		ESRF (n = 24)		Multiples of the identified conditions (n=105)	
Length of stay on last admission (d)	Median	(range)	Median	(range)	Median	(range)	Median	(range)	Median	(range)
	6.0	(3 – 14)	6.0	(1 – 49)	5.0	(1 – 38)	6.5	(0 – 60)	5.5	(1 – 140)
Admission team	n	%	n	%	n	%	n	%	n	%
- Any specialist team (condition specific, MDT)	139	57.7	37	66.1	31	55.4	11	45.8	60	57.1
- Generalist team ONLY (gen med, ED)	90	37.3	16	28.6	20	35.7	10	41.7	44	41.9
- Unknown admission team	12	5.0	3	5.4	5	8.9	3	12.5	1	1.0
Further classifications										
- Condition specific medicine	66	27.4	24	42.9	13	23.2	6	25.0	23	21.9
- General medicine	149	61.8	29	51.8	34	60.7	11	45.8	75	71.4
- Emergency dept	92	38.2	23	41.1	21	37.5	5	20.8	43	41.0
- Multiple teams	116	48.1	28	50.0	26	46.4	9	37.5	53	50.5
Referred to hospital by										
- Self or family	124	51.5	31	55.4	26	46.4	13	54.2	54	51.4
- Nurse	54	22.4	8	14.3	16	28.6	3	12.5	27	25.7
- Specialist	30	12.4	9	16.1	9	16.1	3	12.5	9	8.6
- GP	22	9.1	5	8.9	1	1.8	2	8.3	14	13.3
- Ambulance	1	0.4	0	0.0	0	0.0	0	0.0	1	0.4
- Not documented	10	4.1	3	5.4	4	7.4	3	12.5	0	0.0

of 235 decedents with documented information regarding private health insurance status had cover (n = 52 of 235 reported, 22.1%). Level of coverage for decedents with private healthcare insurance was not collected, though it is noted that many Australians with private health insurance have hospital-only cover which does not include many specialists or outpatient services.

Terminal Admission

During the terminal admission, decedents were admitted under a range of generalist (including emergency department) and/or specialist teams (including condition specific or multiple teams; Table 2). More than half of decedents (n = 139, 57.7%) had some form of subspecialist involvement (e.g., respiratory medicine) documented within their admitting team, which was most frequent amongst decedents with COPD only (n = 37, 66.1%). Referral to hospital was primarily through self-presentation or through family (n = 124, 51.5%).

Outpatient Care

Most decedents (n = 178, 73.9%) accessed some form of specialist outpatient services for their chronic conditions (Table 3). Private physicians (n = 91, 37.8%) and chronic disease programs (n = 61, 25.3%) were the most commonly accessed specialist outpatient care providers, with relatively few having documented access to a specialist nurse (n = 17, 7.1%).

Three quarters of decedents (n = 183, 75.9%) had received some form of symptom management education, which was often provided by multiple healthcare professionals. Symptom management education was comparably high across decedents with COPD only (n = 45, 80.4%), CCF only (n = 44, 78.6%) and those with multiple conditions (n = 81, 77.1%), but was markedly less common in those with ESRF only (n = 11, 45.8%).

Additionally, 43.2% (n = 104) received documented outpatient education related to chronic disease management, this was most common in people living with COPD only (n = 34, 60.7%), and less so in those with multiple conditions (n = 44, 41.9%), CCF only (n = 22, 39.3%) or ESRF only (n = 4, 16.7%).

Palliative Care and Advance Care Planning

Almost one third (n = 74, 30.7%) of decedents were referred to palliative care during their final admission and one fifth (n = 49, 20.3%) had documentation of some palliative care input prior to terminal admission (Table 4). Referral to palliative care during or prior to the terminal admission was least common in decedents with CCF only (n = 11, 19.6% for terminal admission; n = 9, 16.1% for previous input).

Just over half of decedents had documented NFR orders (n = 139, 57.7%), with this documented as occurring, on average, 2.12 admissions prior to death. Other indicators of end-of-life planning, including ACP (n = 71, 29.5%), spiritual support (n = 18, 7.5%), and multidisciplinary planning meetings (n = 7, 2.9%) were less common. There was little evidence of documentation of preferred place of death (n = 18, 7.9%), however, actual place of death was documented in just over a half of decedents files (n = 137, 56.8%) with decedents most frequently dying in hospital (n = 97, 70.8%).

Table 3
Outpatient Care

Previous outpatient care for chronic conditions	Total (n = 241)		COPD (n = 56)		CCF (n = 56)		ESRF (n = 24)		Multiple conditions (n = 105)	
Outpatient care provided by:	n	%	n	%	n	%	n	%	n	%
- Any specialist service (private physician, chronic disease program, advanced diseases service, spec nurse)	178	73.9	43	76.8	45	80.4	15	62.5	81	77.1
- Generalist service ONLY (Gen med, gen disease program)	49	20.3	13	23.2	11	19.6	9	37.5	24	22.9
- Outpatient care provisions unknown	14	5.8	2	3.6	5	8.9	3	12.5	4	3.8
Further classifications										
- Private physician	91	37.8	25	44.6	26	46.4	7	29.2	33	31.4
- Chronic disease program	61	25.3	12	21.4	13	23.2	4	16.7	32	30.5
- General medicine	54	22.4	13	23.2	6	10.7	7	29.2	28	26.7
- Advanced chronic disease service	31	12.9	9	16.1	8	14.3	2	8.3	12	11.4
- General disease program	30	12.4	9	16.1	8	14.3	2	8.3	11	10.5
- Specialist nurse	17	7.1	3	5.4	4	7.1	2	8.3	8	7.6
- Other	15	6.2	6	10.7	3	5.4	1	4.2	5	4.8
Symptom management education										
- Yes	183	75.9	45	80.4	45	80.4	11	45.8	82	78.1
- No	58	24.1	11	19.6	11	19.6	13	54.2	23	21.9
Provided by:										
- Doctor	180	74.7	45	80.4	44	78.6	10	41.7	81	77.1
- Nurse	167	69.3	42	75.0	43	76.8	11	45.8	71	67.6
- Physiotherapist	96	39.8	22	39.3	25	44.6	6	25.0	43	41.0
- Occupational Therapist	32	13.3	8	14.3	8	14.3	3	12.5	13	12.4
- Pharmacist	5	2.1	0	0.0	2	3.6	0	0.0	3	2.9
- Other	73	30.3	17	30.4	20	35.7	6	25.0	30	28.6
Outpatient education for chronic disease management	104	43.2	34	60.7	22	39.3	4	16.7	44	41.9

End of Life Care Symptom Support

Opioids were prescribed to 45.2% (n = 109) of decedents, with the most commonly recorded indications being pain (n = 28, 25.7%) and dyspnoea (n = 9, 9.3%), however the majority of decedents receiving opioids did not have clearly documented indication (Table 5). Pressure area care (n = 94, 39.0%) and dyspnoea management (n = 90, 37.3%) were also documented in over a third of decedents, with the former most commonly in people with ESRF only (n = 14, 58.3%) and the latter in people living with multiple conditions (n = 45, 42.9%). Decedents with ESRF only were most frequently reviewed for cessation of non-essential medications (n = 13, 54.2%) or blood tests (n = 12, 50.0%).

Patient and Care Factor Effect on Palliative Care Indicators

Exploratory analysis of differences in indicators of palliative care referral/involvement across patient/care characteristics showed consistent statistically significant differences for all indicators depending on location of terminal admission ($P \leq 0.001$; Table 6). Previous palliative care involvement ($P < 0.001$), documented completion of NFR ($P < 0.001$), and review/cessation routine blood tests ($P = 0.003$) all significantly differed depending on involvement of a specialist admitting team, whilst only previous palliative care input differed depending on involvement of specialist outpatient contact ($P < 0.001$). Previous palliative care input ($P = 0.003$) and completion of both NFR ($P = 0.001$) and ACP ($P < 0.001$) all significantly differed between those with and without documented symptom management education. Completion of NFR also varied depending on CCI ($P = 0.002$). No significant differences in any indicators of palliative referral/involvement were detected as an effect of age, sex, primary diagnosis, or living arrangements.

Discussion

This audit of decedents with primary diagnoses of COPD, CCF, or ESRF across five regional health services in the Australian state of Victoria found that although specialist chronic disease management was relatively common, involvement of palliative care and formal documentation of ACP were limited.

The majority of decedents identified in this audit had multiple diagnoses with the conditions of interest, which represents the high degree of comorbidity, or 'multimorbidity', that commonly occurs amongst patients with chronic disease.[23] Managing the complex, often unmet needs of a growing population of

Table 4

Palliative Care and Advance Care Planning

Advance care	Total (n = 241)		COPD (n = 56)		CCF (n = 56)		ESRF (n = 24)		Multiple conditions (n = 105)	
	n	%	n	%	n	%	n	%	n	%
Referred to palliative care	74	30.7	22	39.3	11	19.6	11	45.8	30	28.6
Previous palliative care input	49	20.3	16	28.6	9	16.1	5	20.8	19	18.1
Documentation of MDT planning meeting	7	2.9	2	3.6	1	1.8	1	4.2	3	2.9
Prior completion of hospital NFR	139	57.7	29	51.8	28	50.0	8	33.3	74	70.5
	Mean (SD)	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**	**Mean (SD)**	**range**
Number of admissions prior documentation of NFR	2.12 (2.838)	0 - 16	1.97 (2.814)	0-12	2.27 (3.065)	0-11	0.83 (1.030)	0-3	2.31 (2.838)	0-16
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Documentation of person/relative aware of plan	89	36.9	15	26.8	16	28.6	14	58.3	44	41.9
Prior completion of formal advance care planning	71	29.5	15	26.8	18	32.1	6	25.0	32	30.5
Documented advance care planning discussion but no outcome achieved due to patient/family wishes	10	4.1	2	13.3	2	11.1	0	0.0	6	18.8
Documented preferred place of death	18	7.9	3	5.4	3	5.4	2	8.3	10	9.6
Location of preferred place of death										
- Home	10	4.1	1	1.8	3	5.4	2	8.3	4	3.8
- Hospital	4	1.7	1	1.8	0	0.0	0	0.0	3	2.9
- Hospice or community respite	2	0.8	0	0.0	0	0.0	0	0.0	2	1.9
- Nursing home care facility	2	0.8	1	1.8	0	0.0	0	0.0	1	1.0
Documented place of death	137	56.8	23	41.1	31	55.4	15	62.5	68	64.8
Place of death location	N = 137		N = 23		N = 31		N = 15		N = 68	
- Hospital	97	70.8	14	61.0	18	58.1	13	86.7	52	76.5
- Community care or hospice	32	23.4	7	30.4	11	35.5	2	13.3	12	17.6
- Aged care specifically	5	3.6	1	4.3	1	3.2	0	0.0	3	4.4
- Home	3	2.2	1	4.3	1	3.2	0	0.0	1	1.5

Table 5

End of Life Care

End of life care management	Total (n = 241)		COPD (n = 56)		CCF (n = 56)		ESRF (n = 24)		Multiple conditions (n = 105)	
	n	%	n	%	n	%	n	%	n	%
Opioids prescribed	109 45.2	45.2	22	39.3	20	35.7	15	62.5	52	49.5
Indication of opioids	N = 109		N = 22		N = 20		N = 15		N = 52	
- Pain	28	25.7	2	9.0	3	15.0	8	53.3	15	28.8
- Shortness of breath	9	8.3	4	18.1	0	0.0	2	13.3	2	3.8
- Both pain and SOB	6	5.5	2	9.0	2	10.0	0	0.0	1	1.9
- Agitation	2	1.8	0	0.0	0	0.0	0	0.0	2	3.8
- Both pain and agitation	2	1.8	0	0.0	1	5.0	1	6.7	0	0.0
- End of life care	1	0.9	0	0.0	0	0.0	0	0.0	2	3.8
- Seizures	1	0.9	0	0.0	0	0.0	0	0.0	1	1.9
- Both pain and EOLC	1	0.9	0	0.0	0	0.0	0	0.0	1	1.9
Pressure area management	94	39.0	17	30.4	19	33.9	14	58.3	44	41.9
Dyspnea management	90	37.3	17	30.4	18	32.1	10	41.7	45	42.9
Oxygen therapy	89	36.9	19	33.9	17	30.4	11	45.8	42	40.0
Pain management plan	88	36.5	17	30.4	18	32.1	11	45.8	42	40.0
Secretion/mucus membrane management	88	36.5	18	32.1	18	32.1	12	50.0	40	38.1
Review of nonessential medications	86	35.7	12	21.4	15	26.8	13	54.2	46	43.8
Review/ceased routine blood tests	78	32.4	11	19.6	14	25.0	12	50.0	41	39.0
Nausea management	61	25.3	13	23.2	15	26.8	4	16.7	29	27.6
Syringe driver in place	51	21.2	8	14.3	11	19.6	8	33.3	24	22.9
Clinically assisted nutrition/hydration	40	16.6	10	17.	9	16.1	1	4.2	20	19.0
Ventilation NIV	28	11.6	8	14.3	6	10.7	2	8.3	12	11.4
Exercise for comfort	20	8.3	5	8.9	6	10.7	1	4.2	8	7.6
Documentation of spiritual support	18	7.5	2	3.6	3	5.4	4	16.7	9	8.6

Table 6

Associations Between Patient/ Care Characteristics and Palliative Care Referral/Involvement

	P value (one-way ANOVA)					
Independent Factor	Palliative care referral	Previous palliative care input	Completion of NFR	Completion of ACP	Review of non-essential meds	Review and cessation of routine blood tests
Sex	0.338	0.109	0.573	0.370	0.616	0.653
Age	0.528	0.696	0.777	0.535	0.429	0.621
Charleston Comorbidity Index 10-year survival (CCI)[a]	0.013	0.064	**0.002**	0.825	0.935	0.208
Primary diagnosis	0.039	0.351	0.010	0.883	0.166	0.386
Location of terminal admission	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**0.001**	**0.001**
Living arrangements (alone vs with others)	0.789	0.688	0.046	0.289	0.256	0.882
Specialist admitting team	0.154	**<0.001**	**<0.001**	0.150	0.016	**0.003**
Specialist outpatient contact	0.964	**<0.001**	0.248	0.006	0.049	0.020
Palliative care referral	-	**<0.001**	0.078	0.757	0.040	0.023
Previous palliative care input	**<0.001**	-	**<0.001**	0.370	0.008	**<0.001**
Prior completion of NFR	0.078	**<0.001**	-	0.469	0.678	0.468
Prior completion of ACP	0.757	0.370	0.469	-	0.549	0.665
Documented preferred place of death	0.735	0.423	0.952	**<0.001**	0.669	0.685
Actual place of death	0.005	**<0.001**	0.471	**<0.001**	0.027	**0.002**
Opioid use	0.084	0.093	0.014	0.746	0.146	0.729
Review of non-essential medications	0.040	0.008	0.678	0.549	-	**<0.001**
Review/ceased routine blood tests	0.023	**<0.001**	0.468	0.665	**<0.001**	-
Symptom management education	0.747	**0.003**	**0.001**	**<0.001**	0.036	0.044
Length of stay	0.144	0.391	0.460	0.077	0.965	0.943

[a] Kruskal-Wallis test used due to nonparametric data.

multi-morbid chronic disease patients has been flagged as a research priority.[24,25] The degree of documented palliative care involvement was low across the board, with less than a third of decedents referred to specialist palliative care services. Palliative care is most effective when initiated early, so that clinicians are able to deliver ongoing and individualized patient-centered care,[26,27] yet only one in five decedents in our study had specialist palliative care input prior to their terminal admission. This represents a slight improvement when compared with earlier estimates (~14%) regarding palliative care provision to people with nonmalignant disease in Australia in 2009-2010, yet is still considerably lower when compared to decedents with cancer, of whom up to 70% receive palliative care within the last year of life.28

Documented palliative care involvement varied considerably depending on the primary diagnosis. Decedents with COPD, ESRF, or multiple diagnoses were referred to palliative care considerably more frequently than those with CCF only. This is despite clinical guidelines both in Australia[29] and internationally[30] recommending palliative care referral for patients with CCF. The low referral rates, particularly amongst decedents with CCF in the current audit, may reflect differing levels of multidisciplinary integration or palliative care awareness across different physician subspecialties. It is noted that many decedents in the current audit had multimorbidity which may obscure the true rate of palliative care involvement for certain conditions where multimorbidity was more common.

Exploratory univariable analyses of patient and care characteristics associated with differences in key indicators of palliative care involvement highlighted specialist care involvement was associated with increased frequency of end-of-life care, including ACP and NFR documentation. Unsurprisingly, previous palliative care involvement was also frequently associated with other indicators of quality end-of-life care, including documented ACP and NFR orders, symptom management education, and review and cessation of unnecessary pathology and medications at end-of-life. This is consistent with evidence that early palliative care involvement for people with chronic disease is effective at improving patient-reported health outcomes.[31–33]

Of note, no demographic characteristics, including age, sex, primary diagnosis, or living situation were associated with indicators of palliative care. This is in contrast to previous analyses of palliative care recipients where decedents who were female, had a partner, and lived in private residence were more likely to receive palliative care.28 Given the exploratory nature of these analyses and relatively small sample size, it is important not to rule out the influence of demographic characteristics on access to palliative care.

Frequency of palliative care involvement indicators differed significantly across the five services included in this study and likely reflects resource limitations at smaller health services. This is consistent with our earlier survey of regional health services in Victoria, which demonstrated that referral and management pathways for palliative care services for people with chronic nonmalignant disease are often ad-hoc.20 Lack of formalized palliative care is not unique to rural and regional areas, but it is exaggerated by scarcity of resources and staffing relative to metropolitan areas.[34,35] Despite the well-recognized need for palliative care services for people with chronic disease, the lack of formalized referral and management pathways are common barriers to earlier involvement of specialist palliative care services.[36,37]

Conclusions

The findings of this study echo earlier reports of limited formal palliative care pathways and lack of resources for patients with chronic disease in regional and rural Australia[20] and reinforce the relationship between palliative care input and indicators of patient-centered end-of-life care. The relatively low level of palliative care referrals, particularly the lack of referrals prior to terminal admission, represent missed opportunity to improve patient outcomes in the final years of life. Adequate resourcing and interdisciplinary care are needed to ensure equitable access to palliative care services in regional and rural areas.

Disclosures

The authors declare that there is no conflict of interest.

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