



Palliative care and psychosocial care in metastatic non-small cell lung cancer: factors affecting utilisation of services and impact on patient survival

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Abstract

Background Palliative care (PC) and psychosocial care (PSC) are essential services, which can positively impact on quality of life in patients with metastatic lung cancer, when advanced disease and poor prognosis preclude the use of curative therapies. The aims of this study were to describe patterns of PC and PSC and identify factors associated with service utilisation and overall patient survival.

Method A retrospective Australian cohort of South Western Sydney residents with newly diagnosed stage IV non-small cell lung cancer (NSCLC) in 2006–2012 was identified from the Local Health District Clinical Cancer Registry. Supplemental information was sourced from the area PC database and hospital medical records. Cox regression models with robust variance identified factors associated with PC and PSC and examined patient survival.

Results A total of 923 patients were identified. Eighty-three per cent of patients were seen by PC, with 67% seen within 8 weeks of diagnosis. PSC utilisation was 82%. Radiotherapy treatment and residential area were associated with both PC and PSC. Increasing age was associated with early PC referral. Median overall survival was 4 months. PC was associated with patient survival; however, the effect varied over time.

Conclusion The rate of PC and PSC in our metastatic NSCLC population was high when compared with published data. Despite this, there were gaps in PC and PSC provision in this population, notably with patients not receiving active treatment, and those receiving systemic therapy utilising these services less frequently. PSC and PC contact were not convincingly associated with improved patient survival.

Keywords Lung neoplasms · Palliative care · Psychosocial care · Survival · Service utilisation

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Introduction

Prognosis for patients diagnosed with metastatic lung cancer is poor, with estimated 1-year survival in Australia at 19% [1] and published international rates between 16 and 26% [2]. In non-small cell lung cancer (NSCLC), half present with metastatic disease which precludes curative treatment and the care of these patients is usually palliative or supportive in nature.

Palliative care (PC) is an approach aimed at the prevention and relief of pain and other symptoms, and encompasses holistic support and management to assist patients and families facing life-threatening disease. Integrated and early approaches to PC in lung cancer have been associated with better patient outcomes, including improved quality of life (QoL), reduced rates of aggressive care at end-of-life and survival improvement in select patient groups [3, 4].

Similarly, evidence suggests that psychosocial care (PSC) positively impacts NSCLC patients. PSC incorporates the management of patient's psychological, social and emotional wellbeing in the context of their cancer diagnosis and is provided by specialist caregivers. Specifically, nursing-led coordination of care improves symptom management and referral pathways to key services; counselling can assist with patient coping skills, and psychological support and educational interventions may improve patient QoL [5].

We found a lack of population-based actual utilisation rates for both of these important services for NSCLC patients in the literature, with many studies typically observed in selected clinical trial or decedent populations, making comparison of local utilisation rates and benchmarking difficult. The aims of this study were to describe patterns of PC and PSC, and characterise factors associated with service utilisation and patient survival for those diagnosed with metastatic NSCLC. Given the growing evidence for improved patient survival with the receipt of early and integrated PC services, we also wanted to examine patient outcome to identify if PC or PSC contact impacted on our population's survival.

Methods

Data source and population

A retrospective cohort of patients with newly diagnosed stage IV NSCLC was identified from the South Western Sydney Local Health District Clinical Cancer Registry (CCR). Cases included were diagnosed between 01/01/2006 and 31/12/2012 and resided within local postcode boundaries.

The CCR is a patient-based repository of agreed, notifiable cases of malignancy that are diagnosed and/or treated within local public hospital facilities from 1/1/2006. Data is retrospectively collected from primary sources, including hospital electronic medical records and oncology information system

records. Information is coded and validated by Cancer Information Managers to improve completeness and quality.

The Local Health District covers one of the largest geographic areas in the state and the region holds a population close to one million. It has a highly culturally diverse populace and also has some of the most socioeconomically disadvantaged communities in the state [6]. As a result, the vast majority of lung cancer treatment and management occurs within the public sector.

Data definitions

During the study period, PC services for the district included specialist consultancy covering all public hospitals and community-based nursing-led home visits. Patients who had a consultation with a PC clinician or nurse and/or admission to any of these facilities were categorised as receiving PC. Early contact with PC was defined as interaction initiated within 8 weeks (56 days) of diagnosis. This arbitrary cut-off was selected based on the landmark Temel clinical trial (2010) [4], where patients were randomised to an early PC intervention by 8 weeks post-diagnosis.

We defined PSC as the receipt of care at any time after diagnosis, from any of the following providers: social work, psychology or psychiatry, specialist nursing coordinator and others (including support groups, counselling and pastoral care). This data domain and definition are specified by the CCR minimum data set and are routinely collected.

We present patients with any identified contact with PC and PSC services, irrespective of whether a referral was identified. Patient contact with services were identified and validated using the District Palliative Care database, Oncology clinic lists, electronic medical records and hospital inpatient [7] and outpatient admissions and attendances. Where information could not be identified to support contact with each service provider or care type, the assumption was made that contact did not occur. In an effort to improve the quality and completeness of the data, the authors undertook a quality assurance and validation check of the data across key variables related to palliative and psychosocial care receipt, consultation dates and anti-cancer treatments received before data analysis.

Local resident suburbs were sub-grouped using statistical areas defined by the Australian Bureau of Statistics [8]. These areas were then assigned into three larger geographical regions focussed around oncological care hubs in the LHD for analysis: Fairfield/Liverpool, Bankstown and Outer SWS. Oncology treatment provided within SWSLHD public facilities are focussed in three major Cancer Therapy Centres, with one located in each of the geographic regions. All treatment described refers to active anti-cancer treatment, including surgery, radiotherapy and systemic therapies, provided with any

intent and given at any time between diagnosis and death. Systemic therapy includes the receipt of any chemotherapeutic or targeted agent.

Data on tumour stage were collected in accordance with the American Joint Committee on Cancer (AJCC) TNM Classification of Malignant Tumours, 7th Edition [9]. Socioeconomic status (SES) was classified according to Australian Bureau of Statistics Socio-Economic Indexes for Areas Index of Relative Socio-Economic Disadvantage (IRSD) for residential area displayed as quintiles of disadvantage, with the 1st quintile including the most disadvantaged suburbs [10].

Analysis

Cox regression with robust variance [11] was used to model and obtain relative risks of patient characteristics associated with PC and PSC utilisation in univariate and multivariable models. Death data were collected up to a censor date of 31/12/2013. Deaths were confirmed by New South Wales Registry of Births, Deaths and Marriages. Kaplan-Meier (KM) survival analysis and Cox regression models identified multivariable predictors of patient survival. Results from the regression modelling are presented as relative risk (RR), hazard ratio (HR) and parameter estimates with associated 95% confidence intervals (CI). A *p* value cut-off of < 0.05 was used to indicate statistical significance. Data analysis was performed using SAS Enterprise Guide Version 7.1, copyright © 2017 SAS Institute Inc.

Results

A total of 923 patients were identified. Median age was 69 years and 63% were male. Patient characteristics are described in Table 1. Fifty-four per cent of patients were born overseas. Eighty-three per cent of patients were classified with M1b disease (distant metastases) and 17% had M1a (locally advanced and pleural effusion) disease at diagnosis. Fifty-two per cent received radiotherapy and 34% received systemic therapy. No patients received surgery. Median time from diagnosis to first treatment was 28 days. Thirty-five per cent of patients did not receive any treatment. Fifty-one per cent were discussed at a lung cancer multidisciplinary team meeting.

Palliative care

Documented contact with a PC service was identified in 85% (*n* = 789) of cases. Early PC occurred in 67% of cases. Seventy per cent of patients had contact with specialist medical PC clinicians, whilst 15% were identified as having only seen by the Community PC nursing team.

Table 1 Patient characteristics displaying service utilisation by subgroup

	Total (<i>n</i>)	Palliative care, %	Early palliative care, %	Psychosocial care, %
Total (<i>n</i>)	923	790	618	759
Age group				
< 65	299	87	46	88
65–74	295	84	53	79
75–84	258	87	59	81
85+	71	79	72	77
Gender				
Male	578	86	56	83
Female	345	84	50	81
Residential area				
Fairfield/ Liverpool	423	88	58	87
Bankstown Outer SWS	215 285	79 86	46 54	76 81
SES Quintile of Disadvantage				
1st (lowest)	83	88	54	86
2nd	36	69	39	67
3rd	352	82	49	80
4th	166	89	57	81
5th (highest)	286	89	61	86
Diagnosis year				
2006	118	76	42	82
2007	129	77	54	86
2008	142	94	54	82
2009	138	90	54	83
2010	137	92	65	75
2011	122	81	55	81
2012	137	86	55	87
Morphology				
Adenocar- cinoma	369	85	48	82
Large cell	246	87	54	81
Squamous cell	115	90	58	88
Other NSCLC	193	81	64	80
TNM M value				
M1a	158	80	47	76
M1b	765	87	56	84
Multidisciplinary team meeting				
Y	472	89	52	86
N	451	81	56	79
Active cancer treatment				
Y	604	91	50	86
N	319	75	61	74
Systemic therapy				
Y	318	90	31	86
N	605	83	66	80
Radiotherapy				
Y	482	93	57	88
N	441	77	51	76

Table 1 (continued)

	Total (n)	Palliative care, %	Early palliative care, %	Psychosocial care, %
Palliative care				
Y	789			86
N	134			84
Psychosocial care				
Y	759	89	57	
N	164	69	43	

SWS South Western Sydney, SES socioeconomic status, NSCLC non-small cell lung cancer, TNM American Joint Committee on Cancer TNM Classification of Malignant Tumours, 7th Edition

The median time from diagnosis to first PC contact was 34 days. Median time from first PC contact to death was 61 days. Rates of utilisation in 2006–2007 were the lowest at 76%, whilst 2008 and 2010 high, with over 92% of patients seen. On multivariable regression analysis results, patients residing in Bankstown were 10% less likely to have PC in comparison to Liverpool/Fairfield (RR 0.9, 0.84–0.97, $p = 0.0061$) (Table 2). Those patients not in receipt of radiotherapy had a decreased likelihood of PC contact (RR 0.83, 0.79–0.88, $p < 0.0001$). Age was not a significant factor in PC utilisation.

For early PC, we found increasing utilisation with older age. Those aged 85 years and above being up to 20% more likely to receive early PC than 75–84 year olds (RR1.2, 1.07–1.35, $p = 0.0017$). Early PC was affected

Table 2 Multivariable factors associated with utilisation of palliative care and psychosocial care services

		Relative risk	95% CI	p value
Palliative care	Residential area			0.0194
	Fairfield/Liverpool	Reference		
	Bankstown	0.9	0.84–0.97	0.0061
	Outer SWS	0.96	0.91–1.02	0.1751
	Diagnosis year	1.02	1–1.03	0.0434
	TNM M value			
	M1a	Reference		
	M1b	1.05	0.97–1.14	0.2534
	Radiotherapy			
	Received	Reference		
	Not received	0.83	0.79–0.88	< 0.0001
Early palliative care	Age group			0.0193
	< 65 years	Reference		
	65–74 years	0.99	0.87–1.13	0.9006
	75–84 years	0.92	0.81–1.04	0.1966
	85+ years	1.11	0.97–1.26	0.1184
	Diagnosis year	1.03	1.01–1.06	0.0202
	Systemic therapy			
Received	Reference			
Not received	2.37	1.99–2.81	< 0.0001	
Psychosocial care	Residential area			
	Fairfield/Liverpool	Reference		
	Bankstown	0.9	0.83–0.98	0.0103
	Outer SWS	0.93	0.87–0.99	0.0269
	Radiotherapy			
	Received	Reference		
	Not received	0.888	0.84–0.94	0.0001
	Palliative care			
	Received	Reference		
Not received	0.761	0.67–0.87	< 0.0001	

TNM American Joint Committee on Cancer TNM Classification of Malignant Tumours, 7th Edition, SWS South Western Sydney

most by the receipt of systemic therapy. Patients who did not receive systemic therapy were nearly 2.4 times more likely to have early PC (RR 2.37, 1.99–2.81, $p < 0.0001$).

Psychosocial care

PSC was documented in 82% ($n = 759$) of patient records. One third of these patients had contact with more than one PSC provider. Social work was the most commonly utilised service ($n = 701$, 61%), followed by specialist nursing ($n = 241$, 21%), and psychological services ($n = 149$, 13%). On multivariable examination, patients residing in Bankstown and Outer SWS were found less likely to be referred to PSC providers in comparison to those living in Liverpool/Fairfield (Table 2). Patients who did not receive radiotherapy had a decreased likelihood of PSC (RR 0.888, 0.836–0.943, $p = 0.0001$). Patients who had no contact with PC services were also less likely to have PSC encounters (RR 0.761, 0.665–0.872, $p < 0.0001$).

Survival

Of the 923 patients, 889 (96%) had died by the end of follow-up. The median follow-up time was 18 months. The 1-year overall survival was 19%, with a median survival time of 122 days. Multidisciplinary team discussion and Adenocarcinoma tumour morphology were both associated with a decreased risk of death; whilst males, those born in

Australia and those in receipt of radiotherapy, had increased risk of death in the final multivariable Cox model (Table 3).

The receipt of any type of active treatment and the receipt of systemic therapy were associated with improved patient survival. The beneficial effect of the receipt of any active treatment and systemic therapy on patient survival consistently increased over time. PC utilisation was associated with patient survival; however, the effect was inconsistent over time. A higher survival probability was observed in PC patients at diagnosis and in the first 6 months following diagnosis; however, the probability of death at 1 year and beyond was increased, as demonstrated by the change in hazard ratio over time (Table 4) and the Kaplan-Meier survival curve (Fig. 1).

Discussion

We identified high rates of utilisation for PC (85%) and PSC (82%) in the advanced NSCLC population. Many studies documenting PC utilisation are drawn from populations of decedents, whilst ours includes all advanced NSCLC patients diagnosed. A large Australian study reported 68% of all deceased cancer patients utilised specialist PC services [12], with another finding that 62% of deceased metastatic NSCLC patients had PC contact [13]. PC utilisation rates for lung cancer in international cohorts are lower [14, 15] demonstrating fewer than 45% of patients with specialist PC referrals.

Table 3 Multivariable Cox regression for overall patient survival

	Parameter estimate	95% CI	Hazard ratio [^]	95% CI hazard ratio	<i>p</i> value
Palliative care	-0.59	-0.86–0.32			< 0.0001
Palliative care × years	1.06	0.65–1.48			< 0.0001
Received treatment	-0.84	-1.16–0.51			< 0.0001
Received treatment × years	-0.79	-1.23–0.36			0.0004
Received systemic therapy	-1.43	-1.72–1.14			< 0.0001
Received systemic therapy × years	-0.79	-1.17–0.42			< 0.0001
Male	0.31	0.17–0.45	1.36	1.18–1.56	< 0.0001
Australian born	0.15	0.01–0.28	1.16	1.01–1.32	0.0349
Large cell vs adenocarcinoma	0.31	0.14–0.48	1.36	1.15–1.61	0.0003
Other NSCLC vs adenocarcinoma	0.40	0.21–0.59	1.49	1.23–1.81	< 0.0001
Squamous cell vs adenocarcinoma	0.28	0.06–0.49	1.32	1.07–1.64	0.0013
Multidisciplinary team meeting discussed	-0.25	-0.39–0.11	0.78	0.68–0.89	0.0004
Received radiotherapy	0.28	0.05–0.52	1.32	1.05–1.68	0.0193

NSCLC non-small cell lung cancer, CI confidence interval

[^]Time varying hazard ratios are displayed in Table 4

Table 4 Multivariable Cox regression hazard ratios results for overall patient survival for time-varying factors

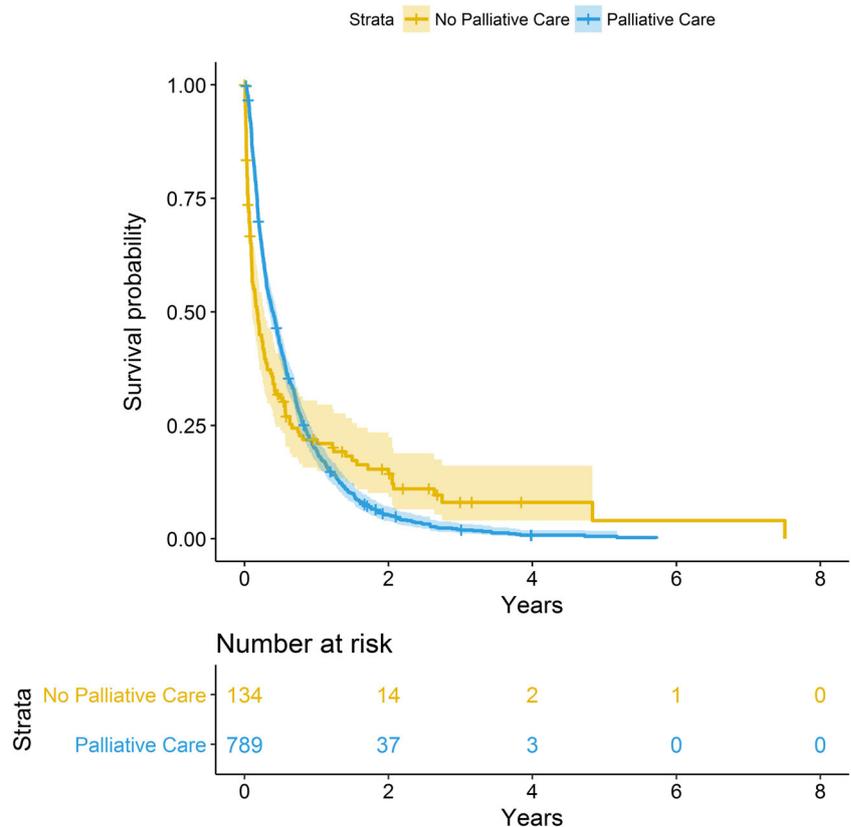
	0 years		6 months		1 year		2 years	
	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI
Palliative care	0.55	0.42–0.72	0.94	0.77–1.15	1.6	1.16–2.19	4.61	2.31–9.19
Received treatment	0.43	0.31–0.6	0.29	0.18–0.47	0.2	0.1–0.38	0.09	0.03–0.26
Received systemic therapy	0.24	0.18–0.32	0.16	0.1–0.25	0.11	0.06–0.2	0.05	0.02–0.13

Direct comparison with international studies is difficult due to varying definitions of PC. Our PC data is focussed on patient interactions with PC specialist clinicians and nurses in both inpatient hospital and community settings. This broadly correlates with the philosophy of UK and US hospice-based care; however, we note that hospice care may include a model of care not necessarily led by PC specialist clinicians. A recent US study describes 74% of patients enrolled in hospice care, yet only 28% of the same group had a specialist PC consultation [3]. Similarly, UK data shows 59% hospice care with a much lower hospital PC consultation rate of 41% [16]. Our data shows 70% of patients with advanced NSCLC had at least one consultation with a specialist medical PC clinician. The quantity, frequency and content of PC interventions could not be assessed using our dataset; however, these factors have been recently identified as wide-ranging and associated with

varying end-of-life patient reported and service delivery outcomes [17].

Early PC has been demonstrated to improve end-of-life care indicators including reduced rates of aggressive end-of-life care and even survival improvements in select patient groups [4, 18]. Definitions of the commencement of early PC vary across studies, usually between 8 and 12 weeks after diagnosis. Our rate of early PC contact is high, at 67%. Retrospective cohort studies where early PC was defined as receipt within a given time before death document much lower rates of utilisation, with some as low as 10.1% [14]. The receipt of PC or PSC is not mutually exclusive, and patients may receive either or both of these defined care types on their cancer journey. We attribute our high utilisation of PC and PSC to well-integrated services within the area’s largest Cancer Therapy Centres (CTCs) and the associated lung

Fig. 1 Kaplan-Meier survival curve for palliative care contact



cancer multidisciplinary team. The PC service for example met 8 of 13 indicators for PC-oncology stream integration [19] throughout the study time period. Multidisciplinary team discussion was identified on univariate analysis to be associated with PC and PSC service utilisation, and this has also been more robustly demonstrated in published local data [20]. The multidisciplinary team is an important funnel for referrals to these important services. The meetings are well attended by PC clinicians, increasing visibility of the service and building professional relationships and referral pathways. Throughout the study time period, the district's smallest cancer centre at Bankstown had an underdeveloped lung multidisciplinary team and disparate PC and oncology services, and this has likely impacted upon utilisation in this residential area. The establishment of a more cohesive lung multidisciplinary team across centres has been a recent priority. A dedicated lung cancer nursing coordinator and other supportive care services were well established at some centres which undoubtedly contributed to the overall high utilisation of PC and PSC. It is worth highlighting that 35% of this population did not receive any anti-cancer treatment. Untreated patients had the lowest rates of PC, early PC and PSC of any other variable tested, although this was not a significant factor in our multivariable models. With most oncology PC and PSC services provided through the cancer centres, untreated patients are undoubtedly missing out on the benefits of an integrated comprehensive cancer service when it comes to referrals for supportive care services.

The receipt of PSC in the NSCLC population has been reported infrequently. An American study found that 33% of metastatic cancer patients were referred to oncology-specific social work and psychology services [21], whilst an Australian qualitative study showed 17% of lung cancer patients were referred for counselling and 6.5% to support groups [22]. In the UK, the National Lung cancer Audit [23] has indicated that up to 84% of patients are seen by specialist nursing teams to guide and coordinate patient care, though the results were highly variable across institutions. We included a number of different PSC sub-types which has contributed to our high utilisation rate as comparison publications have not observed this broad combination of care providers.

Whilst results related to differing utilisation rates between geographic areas and local referral practices over time do not demonstrate large effect sizes, or be generalizable to other populations, we note that the associations around age at diagnosis, and treatment modality on the utilisation of palliative and psychosocial services are clinically and statistically significant. Patient age is a commonly reported factor associated with decreased PC and PSC utilisation. The eldest patients in our cohort were referred to PC and PSC least often overall (though not significant); however, they were referred to early PC significantly more often than their younger counterparts.

Radiotherapy receipt was a significant factor for contact with PC and PSC. In Australia, patients are managed longitudinally by radiation oncologists and initial referral often occurs at the time of diagnosis, with management continuing through to the patient's death. In metastatic lung cancer, radiotherapy is used to improve quality of life through symptom control which parallels the philosophy of PC. Radiotherapy patients were consequently referred to PC and PSC more often. Conversely, patients receiving systemic therapy are those who are fit enough to receive treatment with life-prolonging intent, and patients or clinicians may be more reluctant to connect with PC until later in the disease course. Our data demonstrates this, with patients who did not receive systemic therapy being more than twice as likely to have received a PC within the first 8 weeks post-diagnosis.

Our median time from diagnosis to PC (34 days) is short, and interval from first PC contact to death (61 days) appears to be longer in comparison to current literature from the US [15] and UK populations [16], though direct comparison is challenging due to the age and stage of disease profile of reported populations. Non-receipt of systemic therapy and advanced age in the PC within 8 weeks of diagnosis group are indicative of the short-expected survival of most of our cohort and not necessarily that the patients were referred to PC "early." It does however indicate that patients are being appropriately referred to PC services in line with best practice.

Our study aim was not to gauge survival benefit associated with PC or the timing of initial PC referral and our study design and data limitations mean we are unable to comprehensively demonstrate this. Contact with PC in our population is not causative of death, nor prolonging of survival; but an indication that the sickest patients (likely patients of advanced age and unfit for systemic therapy) with the poorest prognosis are being appropriately referred for supportive care. These findings add to published literature demonstrating importance of early PC services, given that most advanced lung cancer patients are deceased by 1 year post-diagnosis, with as many as 20% dying within 30 days in a recent Irish publication [24]. Whilst their overall prognosis is poor, the addition of early PC gives patients the opportunity to benefit from services before their decline towards death. Patient benefits include a possible improvement in survival, but more importantly in the receipt of less aggressive care at end-of-life, and improved quality of life measures [4].

Patients with adenocarcinoma, those discussed at multidisciplinary team meetings, those receiving treatment, and systemic therapy in particular, experienced improved survival. Male patients, those born in Australia and those receiving radiotherapy and PC had increased risk of death. The differences exhibited by gender and morphology are well documented and our results are consistent with published literature [25]. There is limited evidence to suggest that multidisciplinary team discussion impacts on survival in NSCLC. Our

findings may be related to the proportion of population who are prioritised for meeting agendas. Less than 45% of patients with stage IV lung cancer in our health district were discussed at the multidisciplinary team meeting [20] in this time period. Cases are prioritised for discussion at the meeting by complexity to meet a finite capacity. This enables presentation of patients in whom discussion will have the most benefit, and those discussed may have been patients with better survival prospects. Other prognostic factors, including co-morbidity, performance status and molecular markers could not be investigated using this dataset.

We acknowledge that contact with PC or PSC services may have occurred outside SWSLHD public facilities; however, given the socioeconomic profile of the local community, most would have had their cancer treatment and management within the public sector. Retrospective studies have limitations and inherent selection bias. At the time of manuscript preparation, the data is at least 6 years old. Our study relies heavily on reviewing data which was clinically documented for patient care. Documentation completion and standards were variable, with different services often using different data collection methods with different standards. Documentation of patient activity was also not consistent over time. Despite these challenges, our rates of patient utilisation of PC and PSC are well above those reported by similar investigations. We cannot comment on the number of interventions, or the content of patient management from either PC or PSC providers. Our aim was to describe and investigate patterns of service utilisation, not the consideration of a specific intervention. We were, however, able to comment on the timing of initial contact with PC services using retrospective and routinely collected data.

The identified rate of PC and PSC in our metastatic NSCLC population is high in comparison with published data. Despite this, there are obvious gaps in PC and PSC provision in this population, notably with some residential areas, untreated patients and those treated with systemic therapy receiving fewer referrals to these important services. Further investigation into service gaps may guide service delivery to improve QoL and care for future patients. A follow-up investigation would be of interest to identify if any changes in service provision and practice occurred over time. PSC and PC contact were not convincingly associated with improved patient survival; however, our findings support published evidence and momentum for earlier referral and contact with PC services in this group of patients.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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