Barriers to delivering advanced cancer nursing: a workload analysis of specialist nurse practice linked to the English National Lung Cancer Audit

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ABSTRACT

Purpose: Health services across the world utilise advanced practice in cancer care. In the UK, lung cancer nurse specialists (LCNS) are recognised as key components of quality care in national guidelines, yet access to LCNS contact is unequal and some responsibilities are reportedly left undone. We assess whether any variation in working practices of LCNS is attributable to factors of the lung cancer service at the hospital trust.

Method: Nationwide workload analysis of LCNS working practices in England, linked at trust level to patient data from the National Lung Cancer Audit. Chi-squared tests were performed to assess whether patient contact, workload, involvement in multidisciplinary teams (MDT), and provision of key interventions were related to 1) the trust's lung cancer service size, 2) LCNS caseload, 3) anti-cancer treatment facilities and 4) lung cancer patient survival.

Results: Unpaid overtime was substantial for over 60% of nurses and not associated with particular service factors assessed; lack of administrative support was associated with large caseloads and chemotherapy facilities. LCNS at trusts with no specialty were more likely to challenge all MDT members (80%) compared with those at surgical (53%) or chemotherapy (58%) trusts. The most frequent specialist nursing intervention to not be routinely offered was proactive case management.

Conclusion: Working practices of LCNS vary according to service factors, most frequently associated with trust anti-cancer treatment facilities. High workload pressures and limited ability to provide key interventions should be addressed across all services to ensure patients have access to recommended standards of care.

Keywords: Case management, Clinical Audit, Lung Neoplasms, Nurse Specialists, Survey, Workload

1. INTRODUCTION

The unmatched skillset of nurses in advanced practice is increasingly recognised internationally (de Bont et al., 2016, Steinke et al., 2017). In the UK, clinical nurse specialists are linked to better outcomes for both patients and the local health economies as experienced practitioners providing quality care, leadership and enabling safe release of consultant time (NCAT, 2010, Read and Waters, 2015). Cancer care represents a significant specialist area: particularly lung cancer which accounts for 22% of all cancer deaths in the UK (CRUK, 2014), and studies have shown poor five-year relative survival rates compared with other European countries (De Angelis et al., 2014, Francisci et al., 2015).

Patients and their families gain enormous value from the crucial role lung cancer nurse specialists (LCNS) have throughout the clinical pathway, from breaking significant news to meeting information needs, advocating patient wishes and offering a continuity of care (McPhillips et al., 2014, Mishelmovich et al., 2016, Tod et al., 2015, White, 2013). As financial pressures on health services continue, there have been gains in productivity and cost-effectiveness resulting from LCNS working with people to proactively manage their condition in limiting the progression of disease burden (Baxter and Leary, 2011, Leary and Baxter, 2014).

The Department of Health (England) recommends that specialist nurses should be available throughout the cancer journey and the National Cancer Action Team (NCAT) recognised the unique insight LCNS can provide in multi-disciplinary teams (MDT)(NCAT, 2011). As such, the LUCADA dataset of the National Lung Cancer Audit (NLCA) includes non-mandatory records of initial contact and timing of assessments by LCNS, though data completeness varied between 2007 and 2011; assessment records were missing for 32% and 10% of people, respectively (Khakwani et al., 2016).

With limitations to LCNS metrics considered, the NLCA reports inequalities in access to LCNS workforces between services and that hospital trusts do not always meet the standard of at least

80% of patients seen by a LCNS (RCP, 2015). National audit data has also shown that people diagnosed in trusts with high annual numbers of new patients are less likely to have an initial LCNS assessment whereas those with early stage lung cancer are more likely to be assessed (Khakwani et al., 2016). Whilst there is some recognition for the local cultures and practices that seek to minimise such differences, a recent census of the cancer nurse specialist workforce identified variability in vacancies and caseload (Macmillan, 2017), potentially impacting on the depth and quality of subsequent contact. A survey of 78 LCNS indicated that the majority felt that important work, most often proactive case management, was left undone against best practice (Leary et al., 2014).

We linked insights provided by a nationwide workload survey of 230 LCNS in England to data from the NCAT workforce census and NLCA data from over 125,000 patients diagnosed between 2007 and 2011 to build a comprehensive view of specialist cancer nurse experiences according to factors that described the lung cancer service in which they work. Our aim was to assess whether LCNS workforce, workload, MDT activity and the ability to provide key advanced nursing interventions varied according to the service size, caseload, onsite provision of anti-cancer treatments, and patient survival. Where we identify gaps and barriers to delivering the LCNS role, we highlight strategies to improve resource allocation.

2. METHODS

2.1. Study population and data sources

We used linked data to capture information on people with lung cancer in England and the LCNS workforce across English National Health Service (NHS) trusts (i.e. all hospitals providing lung cancer services across the country). To obtain details of LCNS (including thoracic nurse specialist) working practices across the patient care pathway, we designed a survey disseminated via the National Lung Cancer Forum for Nurses (NLCFN) using Survey Monkey in 2014 (Appendix A). Using the NHS hospital trust code where the LCNS worked, survey data was linked with clinical information from the English NLCA according to hospital where patients first seen, Hospital Episode Statistics (HES) in-patient

data, Office for National Statistics (ONS) mortality data, and with the 2011 NCAT LCNS workforce census in England (NCAT, 2012).

We categorised each trust according to size, LCNS caseload, anti-cancer treatment facilities and survival of its lung cancer patient population. Trust size was measured using NLCA data between 2007 and 2011 to calculate the average number of new lung cancer patients seen annually in each trust, as previously described (Khakwani et al., 2016). Size category of hospital trust was defined: small (<175), medium (175-264), large (≥265). Patients first seen in 2011 plus surviving patients since 2004 were divided by the number of whole time equivalent (WTE) LCNS at a trust to estimate each trust's total caseload per LCNS (Khakwani et al., 2016). Caseload was calculated using the assumption that patients first seen in a particular trust were equally divided between the trust's LCNS team, and remained at that trust throughout the pathway. Trusts were divided into 2 groups based on whether or not they were above the median caseload of 188 patients per LCNS. NLCA and HES data were used to classify trusts according to whether surgery was available (with or without chemotherapy), only chemotherapy was available, or neither treatment facilities were available onsite. A chemotherapy trust was defined by at least 75% of patients receiving an anti-cancer drug at a trust also being first seen there (Powell et al., 2014). To categorise trusts based on the survival of their lung cancer patient population we used median survival information based on ONS date of death for patients first seen in a trust in 2014 (RCP, 2015). The hazard ratio for death following diagnosis was calculated for each trust's patient population compared with the national lung cancer population, adjusting for sex, age, stage, performance status and socioeconomic group. Trusts were categorised as having either average/higher (hazard ratio≤1) or lower (hazard ratio>1) survival compared with the national English lung cancer population.

We used salary and WTE information from the linked NCAT census to calculate the composition of each trust's LCNS team, categorising each LCNS as band 6, 7 or 8. Detailed information on workload and working practices of the hospital trusts LCNS workforce were then obtained from the NLCFN

survey. The workload survey requested contractual and estimated weekly overtime hours which we used to calculate the proportion of WTE hours working overtime. Hours of weekly administrative support as reported by the LCNS were grouped as no support, up to 10 hours, or >10 hours. The survey requested each LCNS to report the point on the patient care pathway at which they first see more than 60% of patients, with answers summarised as before/at or after the lung cancer diagnosis. An estimation of the proportion of new patients seen as emergency presentations was also requested as this is often indicative of a greater severity of disease manifestation. LCNS are considered core members of the lung cancer MDT (NCAT, 2011, NICE, 2011), so the survey ascertained whether they actively attended the MDT, whether they were prepared to challenge all other members of the MDT, and whether they felt uncomfortable or intimidated within the MDT setting. The survey also captured LCNS ability to provide key interventions that are accepted as part of the LCNS role (Baxter and Leary, 2011, Leary and Baxter, 2014, Tod et al., 2015, White, 2013). Respondents were asked which interventions they were routinely able to offer (i.e. to more than 70% of their patients) at each of the following points of the clinical care pathway: before diagnosis, at diagnosis, post diagnosis, treatment, end of treatment, follow-up, disease progression, and end of life care.

2.2. Statistical analyses

We assessed how representative the trusts included in our study were of all English trusts by comparing their treatment facilities, LCNS salary band composition and caseload size. Survey responses regarding LCNS workforce, patient contact, workloads and MDT experience were described as proportions of LCNS survey responses (i.e. the English LCNS workforce captured by the NLCFN survey). Responses on the ability to offer key interventions were aggregated to trust level using the rationale that one affirmation of provision was sufficient to indicate it as being offered by the trust's LCNS team. Variations in reported provision between LCNS at a trust may also be influenced by individual patient-contact patterns across the pathway; trust-level aggregation provided the best description of key interventions available to the patient population. Provision was

assessed at any point of the pathway and then specifically at diagnosis, follow-up (stable disease), and disease progression based on the relative importance of a LCNS offering interventions at these times, compared with other specialist nurses who may be involved at different pathway points (Gardiner et al., 2011, NCAT, 2010, NICE, 2004).

Chi-squared tests were performed to determine whether differences in LCNS patient contact, workload, experience of MDT meetings and capacity to routinely offer interventions were associated with trust size, LCNS caseload, anti-cancer treatment facilities or one-year survival. To assess potential response bias we used chi-squared tests to assess whether missing data on survey responses was related to the four trust factors. A level of 0.05 for statistical significance was used throughout. Data analyses were performed using Stata SE14.

3. RESULTS

A total of 281 responses were collected from LCNS across the UK. Responses from Wales, Scotland, Northern Ireland, and private healthcare institutions were subsequently excluded from this study as linkage was only available with the English NLCA and NCAT data, leaving 230 LCNS (providing 199.7 WTE positions) at 105 NHS hospital trusts. Our survey therefore covered 75.8% of WTE LCNS positions and 69.5% of acute trusts across England (Macmillan, 2014, RCP, 2015). Statistical analysis showed no association with trust inclusion or exclusion according to the treatment facilities, LCNS workforce composition, or LCNS caseload (Supplementary Table 1). Survey response completeness for specific questions ranged from 75.6% (In the last year what proportion of your new patients do you estimate you see as emergency presentations?) to 100% (How many hours of administrative support do you have per week?) and was similar across trust factors (Supplementary Table 2).

Figure 1: LCNS survey responses on patient contact, workload and MDT experience (N=230 LCNS responses across England)

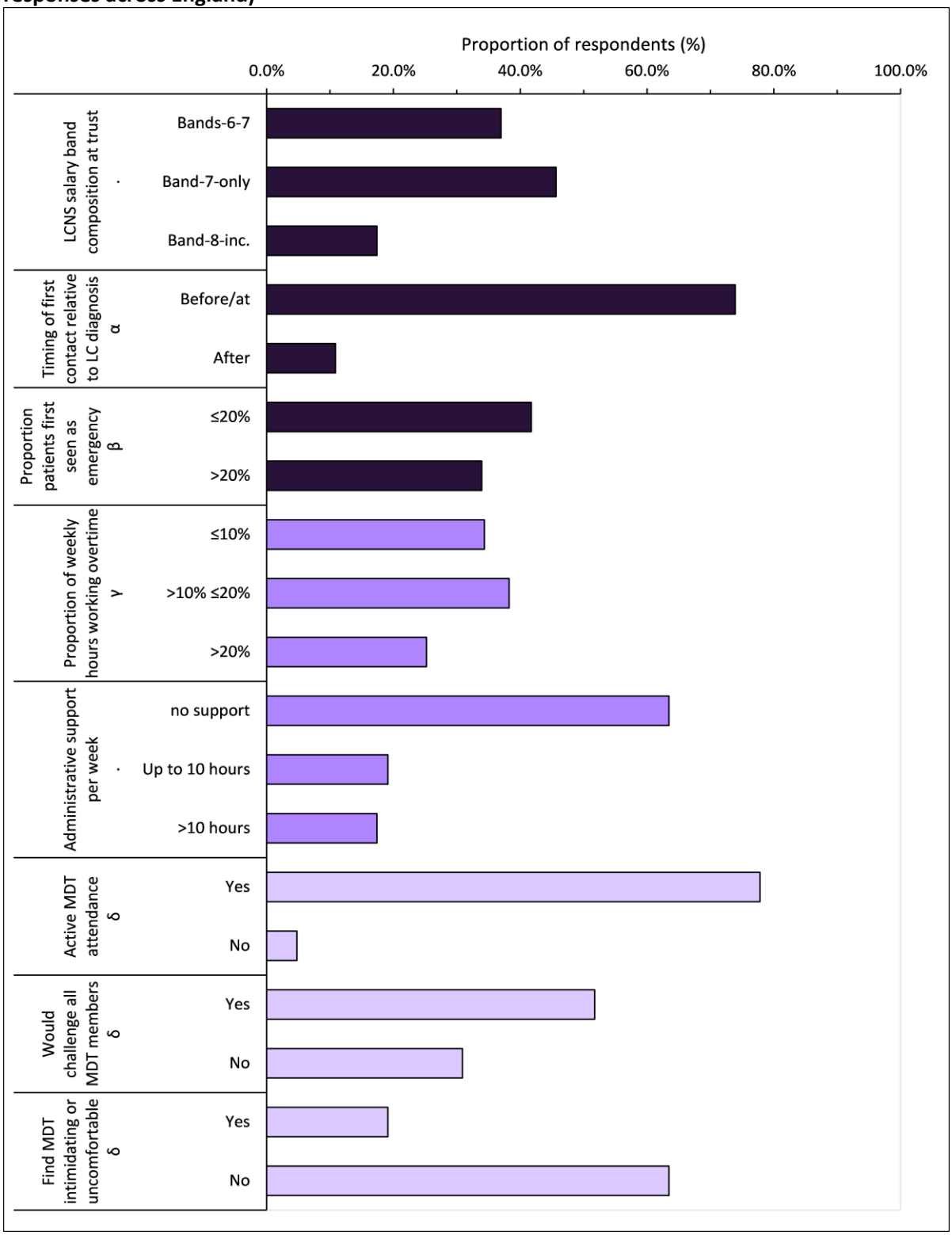

Figure 1 shows the proportion of nurse responses that report a particular working practice in the workload survey (N=230). LCNS – lung cancer nurse specialist; LC – lung cancer; MDT – multidisciplinary team; inc. – included. Percentages do not add up to 100% because of missing data: based on α-195 responses β-174 responses γ-225 responses δ-190 responses. Patient contact – dark bars, workload – light bars, MDT experience – lightest bars.

3.1. Overview of workforce, workload and working practices across English hospital trusts

Figure 1 provides an overview of LCNS survey responses across all trusts represented. Most respondents were at trusts comprising teams of Band-7-only LCNS (45.7%), whilst the smallest proportion of respondents were from teams that included Band 8 LCNS (17.4%). Most respondents (73.9%) indicated that their first contact with the majority of patients was before or at diagnosis and 33.9% reported that more than 20% of their new cases presented as emergencies. With regards to workload, 63.5% reported additionally working over 10% of their weekly hours as overtime and 63.5% reported no administrative support. The majority of respondents (77.8%) had active MDT attendance yet only 51.7% said they would challenge any MDT members and 19.1% found the MDT uncomfortable or intimidating. Two out of nine key interventions (meeting information needs and managing symptom control) were routinely offered by all trusts at some point of the pathway (Figure 2A); this was reported to be slightly lower at diagnosis, follow-up and/or disease progression (offered in 93% and 96% of trusts respectively) (Figure 2B). Conversely, LCNS teams could not routinely offer proactive case management (defined here as regular contact with patients to identify problems earlier) or holistic needs assessment (HNA, defined here as assessing the disease burden and patient needs as a whole) at 17% and 9% of trusts respectively which was higher (31% and 17%) at the important pathway points (Figure 2). Although prevalence of key intervention provision varied, there were no statistically significant associations between routine provision of these key interventions at diagnosis, follow-up or at disease progression according to the trust's service size, LCNS caseload, treatment facilities or lung cancer patient survival (Table 1; Supplementary Table 3).

Figure 2: Number of hospital trusts routinely offering key LCNS workforce interventions (N=100 hospital trusts)

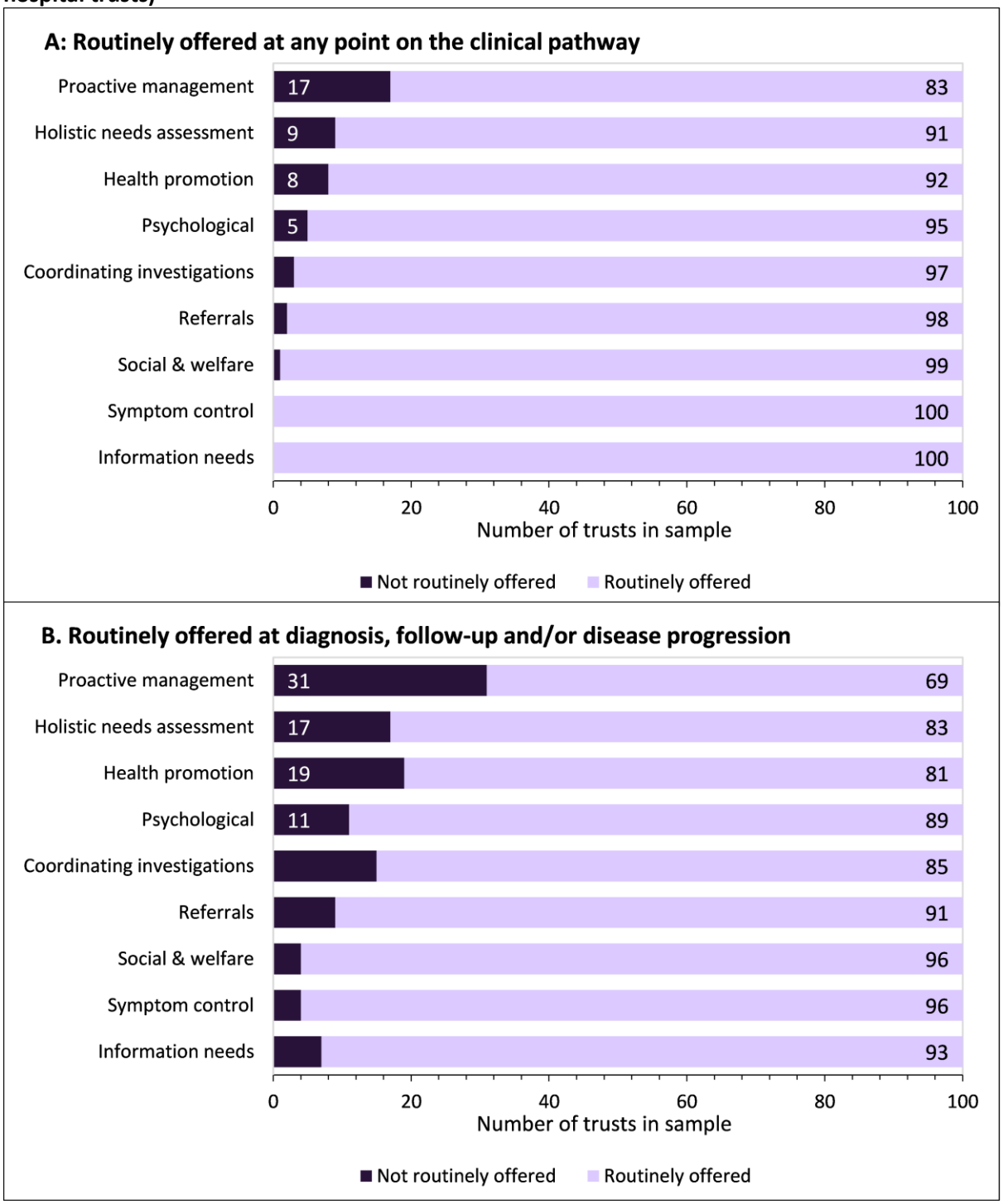

Figure 2 shows the number of trusts that can or cannot routinely offer a key nursing intervention to patients (N=100), based on at least one LCNS within the workforce indicating provision at A) any point of the cancer pathway and B) specific pathway points of diagnosis, follow-up (stable disease) and/or disease progression. Routinely offered was defined as provided to more than 70% of patients. Dark bars– not routinely offered by LCNS at trust, light bars – routinely offered by LCNS at trust.

Table 1: Key interventions not routinely offered by hospital trusts at specific pathway points of diagnosis, follow up, and disease progression (N=100 hospital trusts)						
	Proactive case management			Holistic needs assessment		
	diagnosis	follow up	progression	diagnosis	follow up	progression
Total	44%	45%	45%	25%	56%	46%
LC service size at trust (N)						
Small (48)	44%	44%	42%	25%	50%	40%
Medium (29)	52%	55%	55%	35%	62%	55%
Large (23)	35%	35%	39%	13%	61%	48%
χ^2 p value	0.7	0.5	0.6	0.3	0.7	0.6
LCNS caseload at trust (N)						
Avg./Small (48)	40%	44%	38%	27%	50%	38%
Large (52)	48%	46%	52%	23%	62%	54%
χ^2 p value	0.5	0.9	0.3	0.7	0.4	0.2
Anti-cancer treatment facilities at trust (N)						
No specialty (31)	45%	58%	48%	26%	48%	42%
Surgical (25)	48%	48%	56%	16%	56%	44%
Chemo. only (44)	41%	34%	36%	30%	61%	50%
χ^2 p value	0.9	0.3	0.5	0.6	0.8	0.9
Trust LC survival (N)						
Avg./High (34)	41%	41%	41%	27%	56%	41%
Low* (66)	46%	47%	47%	24%	56%	49%
χ^2 p value	0.8	0.7	0.7	0.8	1.0	0.6

Proactive case management defined as regular contact with patient to identify issues early; holistic needs assessment defined as assessing the disease burden and patient needs as a whole.
*Based on hazard ratio for death after diagnosis >1 compared with national mortality, adjusted for sex, age, stage, performance status and socioeconomic group. LC - lung cancer; LCNS - lung cancer nurse specialist; Avg. - average; Chemo. - chemotherapy; service size based on annual number of new LC patients at trust - Small (<175), Medium (175 <265), Large (≥265); LCNS caseload defined as number of LC patients per full-time equivalent LCNS relative to English median (188) - Avg./Small (≤188), or Large (>188). % - Trusts where LCNS do not routinely offer the intervention as a percentage of trust type.

3.2. Lung cancer service size and caseload

Differences in the composition of LCNS workforce teams, patient contact, workload and MDT experiences according to the size of the lung cancer service and caseload were not statistically significant, with three exceptions (Table 2). A higher proportion (79.7%) of first contacts with patients before/at diagnosis were reported in medium sized services compared with small (71.7%) or large (72.7%) services (p=0.025). LCNS at hospital trusts with high caseloads were more likely to report no administrative support (p=0.048) and that they would challenge any MDT members (p=0.007) compared to those from lower caseload trusts.

Table 2: LCNS working practices according to the size of the lung cancer patient population at the hospital trust where they worked (N=230 LCNS)								
		LC service size of trust				LCNS caseload at trust		
	Total (230)	Small (99)	Medium (59)	Large (72)	χ^2 p:	Avg./Small (108)	Large (122)	χ^2 p:
Workforce features								
LCNS salary band composition at trust								
Bands-6-7	37.0%	29.3%	47.5%	38.9%		35.2%	38.5%	
Band-7-only	45.7%	52.5%	39.0%	41.7%		44.4%	46.7%	
Band-8-inc.	17.4%	18.2%	13.6%	19.4%	0.202	20.4%	14.8%	0.528
Timing of first contact relative to LC diagnosis [α]								
Before/at	73.9%	71.7%	79.7%	72.2%		73.1%	74.6%	
After	10.9%	16.2%	1.7%	11.1%	0.025	14.8%	7.4%	0.102
Proportion patients first seen as emergency [β]								
≤20%	41.7%	40.4%	37.3%	47.2%		37.0%	45.9%	
>20%	33.9%	38.4%	30.5%	30.6%	0.566	39.8%	28.7%	0.077
Overtime & Administrative support								
Proportion of weekly hours working overtime [γ]								
≤10%	34.3%	29.3%	40.7%	36.1%		37.0%	32.0%	
>10% ≤20%	38.3%	42.4%	30.5%	38.9%		38.0%	38.5%	
>20%	25.2%	25.3%	27.1%	23.6%	0.555	23.1%	27.0%	0.678
Administrative support per week								
No support	63.5%	65.7%	61.0%	62.5%		58.3%	68.0%	
Up to 10 Hrs	19.1%	21.2%	20.3%	15.3%		25.9%	13.1%	
>10 Hrs	17.4%	13.1%	18.6%	22.2%	0.554	15.7%	18.9%	0.048
MDT experiences								
Active MDT attendance [δ]								
Yes	77.8%	82.8%	72.9%	75.0%		81.5%	74.6%	
No	4.8%	5.1%	1.7%	6.9%	0.411	2.8%	6.6%	0.158
Would challenge all members [δ]								
Yes	51.7%	49.5%	47.5%	58.3%		44.4%	58.2%	
No	30.9%	38.4%	27.1%	23.6%	0.188	39.8%	23.0%	0.007
Find MDT intimidating or uncomfortable [δ]								
Yes	19.1%	20.2%	23.7%	13.9%		20.4%	18.0%	
No	63.5%	67.7%	50.8%	68.1%	0.209	63.9%	63.1%	0.750

LCNS - lung cancer nurse specialist; LC - lung cancer; MDT - multidisciplinary team; Avg. - average; service size based on annual number of new LC patients at trust - Small (<175), Medium (175 <265), Large (≥265); LCNS caseload defined as number of LC patients per full-time equivalent LCNS relative to English median (188) - Avg./Small (≤188), or Large (>188). % - number of LCNS as a percentage of all LCNS responses; percentages may not add up to 100% because of missing data: p-values based on α-195 responses, β-174 responses, γ-225 responses, δ-190 responses.

3.3. Hospital trust treatment facilities and lung cancer patient survival

LCNS workforce banding was associated with anti-cancer treatment facilities available at the trust (p=0.021), and a higher proportion of respondents from Band-7-only LCNS workforces were identified at trusts with higher average survival (p<0.001) (Table 3). Respondents from surgical trusts

were more likely to first see patients after diagnosis (21.6%) compared with chemotherapy trusts (4.3%) and trusts with no specialty (7.8%) ($p<0.001$). They were also less likely to see patients first presenting as an emergency ($p<0.001$). Trusts with higher survival had higher proportions of patients seen after diagnosis ($p<0.001$) and were less likely to see emergency presentations ($p=0.022$). Proportion of work done as overtime was not associated with trust treatment facilities, but administrative support was ($p=0.002$); the greatest proportion of respondents reporting no support was in trusts offering chemotherapy alone (70.7%), whilst over a quarter of respondents from surgical trusts had more than ten hours available per week. Active MDT attendance was higher in trusts with lower survival ($p=0.002$). LCNS at trusts with no specialty were much more likely to report they would challenge all MDT members (68.8%) compared with LCNS from surgical (43.2%) or chemotherapy (46.7%) trusts ($p=0.005$).

Table 3: LCNS working practices according to anti-cancer treatment facilities and lung cancer survival at the hospital trust where they worked (N=230 LCNS)

		Anti-cancer treatment facilities				LC survival		
	Total (230)	No specialty (64)	Surgical (74)	Chemo. only (92)	χ^2 p:	Avg./High (81)	Low* (149)	χ^2 p:
Workforce features								
LCNS salary band composition at trust								
Bands-6-7	37.0%	34.4%	25.7%	47.8%		17.3%	47.7%	
Band-7-only	45.7%	43.8%	51.4%	42.4%		61.7%	36.9%	
Band-8-inc.	17.4%	21.9%	23.0%	9.8%	0.021	21.0%	15.4%	<0.001
Timing of first contact relative to LC diagnosis [α]								
Before/at	73.9%	81.3%	60.8%	79.3%		67.9%	77.2%	
After	10.9%	7.8%	21.6%	4.3%	<0.001	22.2%	4.7%	<0.001
Proportion patients first seen as emergency [β]								
≤20%	41.7%	45.3%	55.4%	28.3%		51.9%	36.2%	
>20%	33.9%	39.1%	18.9%	42.4%	<0.001	25.9%	38.3%	0.022
Overtime & Administrative support								
Proportion of weekly hours working overtime [γ]								
≤10%	34.3%	25.0%	35.1%	40.2%		30.9%	36.2%	
>10% ≤20%	38.3%	42.2%	35.1%	38.0%		33.3%	40.9%	
>20%	25.2%	31.3%	24.3%	21.7%	0.375	30.9%	22.1%	0.252
Administrative support per week								
no support	63.5%	54.7%	62.2%	70.7%		67.9%	61.1%	
Up to 10 Hrs	19.1%	34.4%	12.2%	14.1%		18.5%	19.5%	
>10 Hrs	17.4%	10.9%	25.7%	15.2%	0.002	13.6%	19.5%	0.483
MDT experiences								
Active MDT attendance [δ]								
Yes	77.8%	84.4%	73.0%	77.2%		79.0%	77.2%	
No	4.8%	1.6%	9.5%	3.3%	0.060	11.1%	1.3%	0.002
Would challenge all members [δ]								
Yes	51.7%	68.8%	43.2%	46.7%		49.4%	53.0%	
No	30.9%	17.2%	39.2%	33.7%	0.005	40.7%	25.5%	0.078
Find MDT intimidating or uncomfortable [δ]								
Yes	19.1%	18.8%	21.6%	17.4%		24.7%	16.1%	
No	63.5%	67.2%	60.8%	63.0%	0.788	65.4%	62.4%	0.274

*Based on hazard ratio for death after diagnosis >1 compared with national mortality, adjusted for sex, age, stage, performance status and socioeconomic group. LCNS - lung cancer nurse specialist; LC - lung cancer; MDT - multidisciplinary team; Chemo. - chemotherapy; Avg. - average; % - number of LCNS as a percentage of all LCNS responses; percentages may not add up to 100% because of missing data: p-values based on α-195 responses, β-174 responses, γ-225 responses, δ-190 responses.

4. DISCUSSION

We found variation in LCNS working practices across hospitals in England which was not directly explained by the size of the lung cancer service or the LCNS caseload. The treatment facilities at the trust and the trust's lung cancer patient survival were associated with whether LCNS were more likely to initially see patients before/at diagnosis, whether they had more patients presenting as emergencies and to some extent with their MDT experience and workload. The majority of LCNS reported to undertake 10% or more of their work as overtime and reported no administrative support, the latter being highest at trusts with facilities for chemotherapy only. At most trusts the LCNS team offered all key interventions across the clinical care pathway, however, some trusts were unable to routinely deliver important aspects of the role at any point of the pathway, proactive case management and holistic needs assessment being not routinely offered at 17% and 9% of trusts respectively. Although variation existed and barriers were identified across hospital-trusts, we found no statistical evidence that the inability to offer key interventions was attributable to the particular trust factors assessed. Our results support recent survey findings of insufficient support and long hours for respiratory nurses (Yorke et al., 2017), whilst we provide specific insight on the LCNS role.

4.1. Strengths and limitations

Previous studies have provided important descriptions of LCNS workload and working practices in the UK (Baxter and Leary, 2011, Leary and Baxter, 2014, Leary et al., 2008, Leary et al., 2014), however no studies have linked survey responses with patient audit data to provide a comprehensive national picture. We used a large representative dataset of people with lung cancer (Rich et al., 2011), and captured the self-declared workload factors of the majority of the English LCNS workforce at the time of our survey; we estimate coverage of 76% of WTE LCNS positions across 70% of trusts. In our analyses, we assumed patients follow the pathway at the hospital where first seen; whilst we recognise that this is not always the reality, we considered it appropriate when modelling caseload as a workforce-dependent extension of service size and in defining lung cancer survival as reported by NLCA, particularly as LCNS act as a key-workers retaining responsibilities

beyond treatment. Caseload may, however, be under-estimated at tertiary centres. We do not report findings at patient level, and whilst we include anti-cancer facilities available as a factor in LCNS experiences, we do not make inference of the treatment pathways patients followed. Our findings offer considerations and cautions for nurses and other healthcare professionals to assist in shaping cancer services.

For trusts not represented by survey respondents, we found no statistically significant differences associated with workforce composition, caseload, or anti-cancer treatment facilities, offering assurance that included trusts represented lung cancer services across England. We also assessed whether response rates for specific questions differed according to trust factors such as size or treatment facilities and found no major indication of response bias. Although the response was high, our sample of 230 LCNS at 105 trusts still resulted in small numbers within certain trust factor categories, so some difference may not have been statistically significant following chi-squared analysis.

4.2. Features of LCNS workforces

The salary band composition of the LCNS workforce was associated with anti-cancer treatment facilities at the trust and lung cancer survival, though a causal relationship was not tested; nurses of higher salary bands had greater representation in higher survival trusts, whilst less than 10% of respondents from trusts with chemotherapy facilities were represented by workforces that included Band 8 LCNS. Commissioning contracted hours at a specified band may not reflect the majority of LCNS hours provided but accountabilities or autonomies related to composition could influence team culture, yet in 2017 lung cancer had the lowest proportion of WTE Band 8 cancer nurse specialists compared to other cancers (Macmillan, 2017). Future study should aim to distinguish the potential contribution of workforce to localised differences in treatment uptake or survival outcomes.

The majority of LCNS respondents who stated seeing most of their patients after diagnosis were from surgical trusts and trusts with higher lung cancer survival, with a majority of LCNS from surgical trusts also seeing fewer patients as an emergency. Such proportions are likely a reflection of nurses working in tertiary or specialist centres who will see patients referred for treatment following diagnosis and thus will have a different relationship with patients compared to local hospital trusts. Irrespective, the prehabilitative role and support from the LCNS pre-treatment in advocating options is vital for the patient and NLCA makes a recommendation that at least 80% of people should have a LCNS present at diagnosis (RCP, 2017, Tod et al., 2015). LCNS teams can reduce inequities in access by offering assessments at the time of diagnosis for all patients wherever possible and ensuring continuity exists for patients referred on to specialist centres.

4.3. Pressures on LCNS workforces

In the UK, LCNS are assigned working hours for which they are expected to undertake clinical roles aligned to the salary banding and specialist nature of the role. Here, we find that most respondents reported working over an additional 10% of their contracted hours, particularly respondents at trusts with no treatment specialty. This demonstrates LCNS dedication to patients and their position whilst also highlights discrepancy in the expectations and reality of demands on specialist time; it is possible that the amount of overtime worked has partially masked the observed influence of caseload size. Hours additionally worked in efforts to maintain standards offered to the caseload should be carefully recorded so that optimal caseloads can be modelled, staffing issues can be predicted early, and safe workloads can be maintained.

Many LCNS spend a large proportion of their time on administrative tasks, which does not make best use of specialist hours and can hinder completion of fuller assessment (Baxter and Leary, 2011, Richardson et al., 2011). LCNS from trusts with small caseloads or with surgical facilities were more likely to report availability of administrative support, although 64% of all respondents indicated no support. This confirms a need to help reduce the administrative burden on LCNS teams across

England, particularly apparent for those with high caseloads or working in chemotherapy trusts. Defined hours of weekly administrative support available to the LCNS team may reduce workload pressure and provide time for clinical, value-adding roles.

4.4. Working practices of LCNS workforces

Proactive case management is the recommended patient-centred approach for specialist nursing across disciplines (Baxter and Leary, 2011, DoH, 2007), and has been shown to reduce administrative burden and emergency admission rates post-diagnosis (Leary and Baxter, 2014). The importance of this work has also been described for patients paralysed by terror or blindsided by diagnosis (Carter-Harris et al., 2015). We have shown that proactive case management and HNA were the interventions that most LCNS respondents were unable to routinely offer to patients across the pathway. Such findings are in agreement with nurse views of reactive care and work left undone (Leary et al., 2014), although we identified variation according to trust factors. Almost all nurses at medium sized services see patients before/at diagnosis yet many cannot offer HNA and most cannot offer proactive case management at this point. Similar findings were observed where caseloads were high, survival was low, and according to different anti-cancer facilities, suggesting a vulnerability to resource issues. To avoid potential gaps in care nurse-led services, such as follow-up clinics, and team remodelling to include a resource of support staff, offer strategies to facilitate proactive patient management and delivery of key LCNS roles (Brummell et al., 2015, Cox and Wilson, 2003, Moore et al., 2002, Moore et al., 2006).

Characteristics of the LCNS role include acting as a 'hub' of the MDT due to their cancer specific expertise and unique knowledge of patient context that allows them to advocate patient wishes (Tod et al., 2015), with presence in MDTs now an explicit UK guideline (NICE, 2011). Non-attendance was greatest in surgical trusts and trusts with higher lung cancer survival, potentially due to workforce representation arrangements or additional commitments. Larger proportions of nurses who reported that they would not challenge all MDT members were associated with trusts that had

smaller caseloads or surgical facilities. These findings may be related to different hospital cultures, such as whether an LCNS chairs the meeting. Similar associations were also found with nurses who felt uncomfortable or intimidated within MDT settings, which highlights an opportunity to improve MDT culture, inclusivity and engagement of all members as integrated care progresses across sectors (Harris et al., 2013, Punshon et al., 2017).

5. Conclusion

We provide evidence of variation in LCNS working practice across hospitals in England, highlighted according to interpretable factors that describe outcomes for patients, access to care or modes of service delivery. A number of LCNS-reported experiences appear to be associated with hospital factors. To ensure the safety of patients and quality of care, including access to appropriate lung cancer treatments, barriers to the delivery of LCNS expertise within an individual's care pathway must be acknowledged and resolved, for instance through local refinement of clinics or supporting staff to enhance resource toward value adding activities. MDT culture also requires review in order to benefit from the unique knowledge LCNS offer, which can impact patient experience and outcomes. This study uses the combined voice of a large sample of English LCNS to provide opportunity for learning and implementation of service developments to support the provision of crucial LCNS roles; we offer recommendations regarding workforce features, support and inclusion, which could lead to gains for the local health economy and provide insight for other health services beyond the UK.

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