The work left undone. Understanding the challenge of providing holistic lung cancer nursing care in the UK

Alison Leary a,*, John White b, Laura Yarnell c,1

a London Southbank University, Faculty of Health & Social Care, LSBU, 103 Borough Rd, London SE1 0AA, United Kingdom
b National Lung Cancer Forum for Nurses, Leeds Teaching Hospitals Leeds General Infirmary, Great George Street, Leeds LS1 3EX, United Kingdom
c National Cancer Action Team, United Kingdom

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Workload
Specialist nurse
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ABSTRACT

In England best practice guidance in cancer recommends that all patients have access to a specialist nurse such as the tumour specific clinical nurse specialist. The role has become pivotal providing aspects of care e.g. meeting information needs, holistic nurse led follow up including symptom control, managing care and providing psychological and social interventions including referral to others in the role of keyworker. There are approximately 295 lung cancer nurse specialists in England and recent study to model optimum caseload used an on line survey to look at workload of lung cancer specialist nurses. A survey of 100 lung cancer nurses from across the UK (RR78%) examined the perception of the work left undone against best practice guidance, caseload size, workload and other factors. 67 of 78 respondents perceived they left work such as proactive management (52) undertaking holistic needs assessments (46) providing appropriate psychological care (26) and meeting information needs (16). The majority (70) worked unpaid overtime (mean 3.8 h range 1–10 h) per week. Although proactive management is thought to result in better outcomes for lung cancer patients in terms of survival, quality of life and decisions of end of life a substantial number of the specialist nurses felt that factors such as caseload and organisational factors inhibited this.

Introduction

Lung Cancer is the most common cause of cancer death in the UK causing 33,400 deaths a year from the 39,000 people diagnosed (CRUK, 2010). In England best practice guidance in cancer has long recommended that all patients with cancer have access to a specialist nurse (DH, 2007). Specialist advanced practice in nursing, often provided through the role of tumour specific clinical nurse specialist (NCAT, 2012) allows the provision of holistic cancer care. The role has become pivotal providing aspects of care such as meeting information needs, holistic nurse led follow up (Moore et al., 2002; NCAT, 2010), managing care (NCAT, 2010; Leary, 2011) and providing psychological and social interventions including referral to others in the role of keyworker (DH, 2007; NCAT, 2010).

Through such access the experience of care is better from the patient perspective (DH, 2011, 2012). However previous work has shown that patient and family access to clinical nurse specialists is not consistent (DH, 2011, 2012; Leary et al., 2011; NCAT, 2012). Evidence suggests that there is variation in the proportion of newly diagnosed cancer patients and numbers of specialist nurses across geography and cancer type (Leary et al., 2011; NCAT, 2012).

This has led to different configurations of services and a probable evolution of the role without strategic intent (Trevatt and Leary, 2010; Vidall et al., 2011). This means there is also a probable variation in workload or complexity of care that tumour specific specialist nurses are able to provide. As part of a larger national study to optimum caseload commissioned for the National Cancer Action Team (NCAT, 2013) an examination of workload of a group of nurses in lung cancer was undertaken to understand the different variables. These variables included demands on nursing time, variation in what services nursing services were offered and variability of service configuration. In addition it was necessary to examine any potential deficit in activity. This was determined by asking the group how much work they felt was “left undone” in that they did not have time or resources to complete the activities recommended by best practice guidance primarily because of caseload size and nature.
In 2011 there were 294.62 lung cancer nurse specialists in England (NCAT, 2012). Data from the National Lung Cancer Audit (NLCA) show that approximately 80% of patients are now seen by a specialist nurse in lung cancer at some point, however, as low as 44% are seen in some cancer networks and some figures at trust level are even lower (NLCA, 2012). In addition data available nationally represents newly diagnosed patients/incidence data. These data are an indication of workload but do not account for on-going caseloads of patients.

Specialist tumour site specific nurses are thought to enhance the quality of care and patient experience (DH, 2011, 2012) and caseloads of patients.

Data are an indication of workload but do not account for on-going level are even lower (NLCA, 2012). In addition data available nationally assessing and meeting information needs of the patient and onwards (NICE, 2004), meeting social and 2007), meeting level two psychological needs including referral to cancer care in the UK, European Journal of Oncology Nursing (2013), http://dx.doi.org/10.1016/j.ejon.2013.10.002

As part of a larger study, the scale and complexity of service provided. It is likely that caseload size and nature is a determinant of workload in terms of time available to provide holistic complex cancer care to the optimum best practice standard. This study examines where the focus of workload for the lung cancer specialist nurse lay and the work that the specialist nurses felt was left undone—-that they regularly felt was not attended to because of capacity issues such as caseload size.

Method

For the purposes of this survey there were six primary categories of activity. This is an oversimplification of the work of the specialist nurse as this work is complex (Leary et al., 2008a) but these are the top level categories of work obtained by parsing of previous data on activity. These categories were: fully meeting information needs about cancer and treatment, proactive management of care for example having the capacity to contact patients if need arises or barriers to providing holistic care or barriers to providing holistic services.

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These results were then analysed using the Survey Monkey analytics package and additional descriptive statistics on Excel.

Results

The response rate was 78% (78 returns from a sample of 100). The respondents were only identified by country of origin and nature of organisation to preserve anonymity.

The group were largely based in England and acute care 98.5% (67), 14.7% (10) were based in England in thoracic oncology (surgical centres). In England one nurse was based in the community (1.5% of total). In the other countries all were based in the acute setting Wales n = 4, Northern Ireland n = 1 Scotland n = 4 and one other (not stated).

In response to the question “what do you consider to be your current caseload including all patients on all part of the pathway?” The majority (n = 33) answered 100–200. The next most common answer was 301–400 (n = 13) and 14 answered in the categories of 401–500 and over 500. This can be seen in Fig. 1.

The nurses were asked which parts of the patient pathway they either participated in or managed as part of a nurse led service in collaboration with a multidisciplinary team (NCAT, 2010) of the 78 managed one or more parts of the patient pathway as a nurse led service. The most common phases for nurse led activity was diagnosis onwards (n = 41) and nurse led follow up in stable disease (n = 41). Such nurse led services are the configuration recommended by best practice guidance in lung cancer nursing (Moore et al., 2002; NICE, 2011; NLCFN, 2009, 2012). 57.4% (35) managed the pre-diagnosis part of the pathway which would include those who are referred but not diagnosed with cancer and would be discharged at that point. Patients who are referred and managed but do not have a cancer diagnosis are unlikely to appear in most caseload/workload calculations. 55.7% (34) managed the progressive disease part of the pathway which is likely to include the prevention of admission for symptom control or end of life care and facilitating care in the community (Quinn, 2011; Baxter and Leary, 2011). Descriptors of nurse led services given in the free text responses were varied and included chemotherapy consent and review clinics, 2nd line treatment clinics and clinics to follow up solitary pulmonary nodules.

The majority (70) regularly worked one or more hours per week unpaid overtime. Previous studies of this group had shown a mean of 6.5 hours per week (Leary et al., 2008b) and similar findings were seen in this study at a mean average of 3.8 hours overtime with a range of 1–10+ hours per week per role (not whole time equivalent – this included data from part time workers in the descriptor fields). 16 members of the group worked 6–10 h or more per week unpaid overtime.

The majority of the group (67) expressed areas of care which they felt that caseload size prohibited them from doing against best practice standards. Respondents could choose more than one area to respond to (total 170 responses Fig. 2).

77.6% (52) felt that they could not proactively manage their caseload using nursing vigilance (that is planned contact and act at times of known higher need) but felt they had to reactively manage care (had to rely on patients contacting them with problems/at points of crisis). Holistic needs assessment has been formalised in England as a best practice standard to assess fully physical and psycho-social needs (CAT, 2007) but 46 felt that they could not regularly offer this to patients. Patients with lung cancer often have high levels of distress and a high need for information however 26 of the respondents felt they did not have time to address psychological issues and 16 felt they could not fully meet information needs. Although cancer patients are more likely to face hardship (Sharp et al., 2013) 17 of the nurses felt they could not address social and financial issues. 13 felt unable to fully address symptom and physical issues due to workload.

In terms of what is left undone and relationship with caseload size there seems to be a relationship in certain areas. Of the 67 nurses who responded to one or more areas (n = 170) there was

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variation as to which areas where related to caseload size however these data might be suggestive of a relationship between amount of categories of work left undone and caseload size in some areas similar to a tipping point (Table 1). More work would need to be done in this area.

The lung cancer specialist nurses in the study were asked to comment on the reasons they felt work was left undone and if caseload size was the only determinant (Table 2). Caseload size was often cited as the main determinant and meant prioritising parts of the patient pathway rather than giving holistic care across the entire pathway or part of the pathway which were part of the service for example:

“I think the size of our caseload prevents us being as proactive as we would like to be – we feel we are a reactive service. It is impossible for us to maintain regular contact with patients and so we are very active at certain points in the pathway, especially around diagnosis and end of life”

Caseload 201–300 group

This was typical of findings in the larger modelling work (NCAT, 2013) the LCNS tended to concentrate on areas that were deemed as most acute.

Even those who answered that work was not left undone questioned the quality of service they wished to provide:
I provide all of the above, but not always to my satisfaction due to pressure of work. Other challenges to providing the service were unfilled vacant posts, colleagues on long term sick leave, financial pressures, being single handed practices with no cover, organisational workforce reviews that appeared to question the value of the role, specialist nurses being asked to take rostered shifts on inpatient wards, lack of administrative support, lack of leadership or support from managers (immediate and/or senior), little opportunity to develop services beyond a minimum, lack of medical staff/staff required to cover several sites (n = 41).

Table 1
The categories of work left undone against caseload size.

<table>
<thead>
<tr>
<th>Estimated caseload size (not incl pre-diagnosis work)</th>
<th>Meeting information</th>
<th>Proactive management</th>
<th>Managing biographical disruption and other psychological issues</th>
<th>Symptom control/physical issues</th>
<th>Social/financial issues</th>
<th>Holistic needs assessment</th>
<th>Total respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–100</td>
<td>5.88%</td>
<td>35.29%</td>
<td>23.53%</td>
<td>0%</td>
<td>0%</td>
<td>35.29%</td>
<td>17</td>
</tr>
<tr>
<td>1</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>101–200</td>
<td>8.70%</td>
<td>28.99%</td>
<td>15.94%</td>
<td>8.70%</td>
<td>10.14%</td>
<td>27.54%</td>
<td>69</td>
</tr>
<tr>
<td>6</td>
<td>20</td>
<td>11</td>
<td>6</td>
<td>7</td>
<td>19</td>
<td>69</td>
<td>69</td>
</tr>
<tr>
<td>201–300</td>
<td>0%</td>
<td>33.33%</td>
<td>20%</td>
<td>6.67%</td>
<td>13.33%</td>
<td>26.67%</td>
<td>89</td>
</tr>
<tr>
<td>0</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>301–400</td>
<td>12.12%</td>
<td>27.27%</td>
<td>12.12%</td>
<td>12.12%</td>
<td>9.09%</td>
<td>27.27%</td>
<td>21</td>
</tr>
<tr>
<td>4</td>
<td>9</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>9</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>401–500</td>
<td>14.29%</td>
<td>33.33%</td>
<td>4.76%</td>
<td>9.52%</td>
<td>14.29%</td>
<td>23.81%</td>
<td>72</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>21</td>
<td>21</td>
</tr>
<tr>
<td>Over 500</td>
<td>13.33%</td>
<td>33.33%</td>
<td>20%</td>
<td>0%</td>
<td>13.33%</td>
<td>20%</td>
<td>80</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Total respondents</td>
<td>16</td>
<td>52</td>
<td>26</td>
<td>13</td>
<td>17</td>
<td>46</td>
<td>170</td>
</tr>
</tbody>
</table>

Table 2
Hours of average unpaid hours worked on a regular basis by caseload size.

<table>
<thead>
<tr>
<th>Caseload size</th>
<th>1 do not/rarely work unpaid overtime</th>
<th>Less than 1 hour</th>
<th>1–2 h</th>
<th>3–4 h</th>
<th>5–6 h</th>
<th>6–7 h</th>
<th>7–8 h</th>
<th>8–10 h</th>
<th>Over 10 h</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q2: 0–100</td>
<td>27.27%</td>
<td>18.18%</td>
<td>36.36%</td>
<td>9.09%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>9.09%</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Q2: 101–200</td>
<td>0%</td>
<td>3.03%</td>
<td>33.33%</td>
<td>36.36%</td>
<td>9.09%</td>
<td>9.09%</td>
<td>3.03%</td>
<td>6.06%</td>
<td>0%</td>
<td>33</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>11</td>
<td>12</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Q2: 201–300</td>
<td>0%</td>
<td>0%</td>
<td>33.33%</td>
<td>33.33%</td>
<td>16.67%</td>
<td>16.67%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>6</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Q2: 301–400</td>
<td>0%</td>
<td>7.69%</td>
<td>30.77%</td>
<td>23.08%</td>
<td>7.69%</td>
<td>7.69%</td>
<td>0%</td>
<td>15.38%</td>
<td>7.69%</td>
<td>13</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Q2: 401–500</td>
<td>0%</td>
<td>0%</td>
<td>14.29%</td>
<td>42.86%</td>
<td>14.29%</td>
<td>14.29%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>7</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Q2: Over 500</td>
<td>0%</td>
<td>0%</td>
<td>28.57%</td>
<td>28.57%</td>
<td>14.29%</td>
<td>0%</td>
<td>0%</td>
<td>14.29%</td>
<td>14.29%</td>
<td>7</td>
</tr>
<tr>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Total respondents</td>
<td>3</td>
<td>4</td>
<td>24</td>
<td>23</td>
<td>7</td>
<td>6</td>
<td>2</td>
<td>5</td>
<td>77</td>
<td></td>
</tr>
</tbody>
</table>

Discussion
The majority of specialist nurses (n = 67, 86%) felt they left work undone against national best practice standards. The primary reasons cited were workload and lack of organisational support. There was a broad spread of work left undone against caseload size. For example the majority of respondents (46) cited holistic needs assessment as presenting a challenge in terms of time despite caseload. Holistic needs assessment comes in many forms but is a complex set of assessments and actions which take around 45 minutes to complete (NCAT, 2013).

Cancer specialist nurses in England regularly report working unpaid overtime (Breast Cancer Care, 2008; DH and Frontier Economics, 2010) as do other specialist nurses working in long term conditions (RCN, 2010; Oliver and Leary, 2010). In this study those with higher caseloads were more likely to regularly work unpaid overtime. The only respondents to not regularly work unpaid overtime were 27% of those with a caseload of less than 100.

In the free text responses (n = 48) 27 report spending expert nursing time doing the essential but non-specialist administrative work which could be done by a secretary or administrator and this is similar to previous studies (Leary et al., 2008a; Breast Cancer Care, 2008; Anionwu and Leary, 2012; Norton et al., 2012).

Work left undone is common in nursing (Ball et al., 2012) and represents a source of dissatisfaction. In the current climate of austerity measures some CNSs are being asked to cut back on study leave and work on the wards. This can be seen as undermining the role of the CNS. The National Lung Cancer Forum for Nurses undertook a survey in 2011 to assess this further and found that 16% of Lung Cancer Nurse Specialists felt their role to be under threat with 10% being asked to work on wards (NLCFN, 2011). Evidence from the Royal College of Nursing (2010) recognises that specialist nursing posts are often placed under threat during times of financial austerity despite the evidence that patients value the services offered by them.

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A major challenge to optimal workload/caseload calculation is the lack of data. Incidence data is collected nationally however no data is collected regarding on-going caseload and in England only partial data is collected on patients who present with the signs and symptoms of lung cancer. A proportion of these patients use lung cancer nurse services but then are diagnosed as benign. These patients are likely to contribute to the lung cancer nurse workload however do not show as part of the national dataset (NLCA, 2012). If employers model workload solely on the basis of incidence this is likely to represent an underestimation.

People with inoperable lung cancer report a higher burden of unmet need, they experience more psychological distress and physical hardship than other tumour sites (Ugalde et al., 2012) making the work of the specialist lung cancer nurse even more relevant. There is also evidence to suggest that proactively managing the care of lung cancer patients in the palliative setting has many positive benefits such as survival, quality of life, mood and less aggressive approaches to the end of life (Temel et al., 2010) and reduced inappropriate admission (Baxter and Leary, 2011). It is of interest to note that the interventions described in the work of Temel et al. (2010) reflect closely the role and interventions of the Lung Cancer Nurse Specialist in the UK. In addition the National Lung Cancer Audit (NLCA, 2012) has shown that patients known to a Clinical Nurse Specialist in lung cancer are more likely to receive treatment (60% v 30%). Researchers and others have attempted to explain this (Roy Castle and NLCFN, 2013) by analysing the patient pathway and the interventions that the Clinical Nurse Specialists provide. With interventions performance status and survival maybe improved, information needs enhanced, decision making better informed and therefore more likely to have treatment. For those Clinical Nurse Specialists who are unable to provide this level of support to patients this could potentially have a negative impact on treatment uptake, quality of life and survival.

The Improving Lung Cancer Outcomes Project (Royal College of Physicians, 2012) found that teams with higher clinical nurse specialist to lung cancer patient ratios were more likely to meet quality performance indicators.

Clinical nurse specialists in lung cancer in the UK provide a valued service however this study shows they perceive a lack of resources and organizational barriers prevent them from fully delivering holistic cancer care to the standard of best practice guidance. Compliance with best practice guidance is more likely to deliver holistic cancer care to the standard of best practice resources and organizational barriers prevent them from fully delivering holistic cancer care to the standard of best practice guidance. Compliance with best practice guidance is more likely to be achieved if these roles are supported by organisations in terms of resources such as secretarial support, appropriate staffing such as filling vacant posts or calculating optimum caseload and managerial support to enable service improvement.

Declared interest

There is no declared interest however the work that this study originated from (optimum caseload calculations) was funded by the National Cancer Action Team.

Conflicts of interest

There is no conflict of interest. This work was not funded but the original caseload calculations work was funded by the National Cancer Action team.

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