THE ROLE OF LUNG CANCER NURSE SPECIALISTS

John White assesses the pivotal part experts play in supporting patients from diagnosis to follow up and survivorship, providing them with information and acting as co-ordinators between individuals and multidisciplinary team members.

Abstract

A report published by the National Lung Cancer Forum for Nurses and the Roy Castle Lung Cancer Foundation examines the contribution of lung cancer nurse specialists (LCNSs) to quality patient care at all stages of the disease pathway. The National Institute for Health and Care Excellence recommends that an LCNS is available at all stages of care, with the UK Lung Cancer Coalition stating that patients should have access to an LCNS for support and advocacy when they need it.

However, growing caseloads, the expectation for all patients to have a holistic needs assessment completed at various points of the pathway, an increasingly complex workload and NHS financial pressures all present potential barriers to the delivery of high quality care for patients. This article examines the complex and varied role of LCNSs. It is important to note that when discussing lung cancer the principles of care also apply to patients with mesothelioma although this disease is not discussed.

Keywords

Care pathway, clinical nurse specialist, lung cancer, patient care, patient outcomes, workforce

LUNG CANCER is the most common cause of cancer death in the UK (Cancer Research UK (CRUK) 2013a). Approximately 41,500 people are diagnosed with lung cancer annually in the UK (Roy Castle Lung Cancer Foundation (RCLCF) 2013), with one third surviving for one year or more and only 8.5 per cent surviving beyond five years (CRUK 2013b).

Recommendations made in the report Understanding the Value of Lung Cancer Nurse Specialists (National Lung Cancer Forum for Nurses (NLCFN) and RCLCF 2013) focus on the difference that lung cancer nurse specialists (LCNSs) can make to the lives of patients and their families and carers. The report is based on a survey of patients and carers and LCNSs’ own accounts of their effect on patient outcomes. The report’s recommendations, combined with national cancer patient experience survey findings (Department of Health (DH) 2012a) and audit data (Health and Social Care Information Centre (HSCIC) 2012), build a compelling picture of the value of LCNSs.

There are 284 LCNSs in England (National Cancer Action Team (NCAT) 2010a) and since the introduction of the role in 1995 there has been an increase in the absolute number of posts. There is variation in access to LCNSs across the UK, with 55 per cent of patients seeing an LCNS at diagnosis, 80 per cent seeing one at any point (HSCIC 2012) and, in England, 90 per cent being given the name of an LCNS (DH 2012a).

The Improving Lung Cancer Outcomes Project (Royal College of Physicians 2012) used the quality outcome measures of ‘patient seeing an LCNS at the time of diagnosis’ and ‘patient seeing an LCNS at defined points along their pathway’ and found that teams with higher ratios of LCNSs to patients were more likely to meet these measures than teams who had lower ratios.

LCNSs who responded to the NLCFN/RCLCF (2013) survey reported that growing caseloads, increasingly complex workloads and bureaucracy were creating
Art & science | patient care

barriers to the delivery of quality care. Some LCNSs said that their volume of work created difficulties in supporting patients throughout the whole care pathway.

Holistic care
The NLCFN/RCLCF (2013) report states that LCNSs are in an ideal position to provide holistic care, ensuring that all patients’ needs are addressed from referral to diagnosis, through treatment and survivorship, and including end of life care.

LCNSs provide support for patients and carers at all stages of the pathway, assessing physical, psychological, social, spiritual and financial needs (NCAT 2007).

The role of the LCNS and its potential effect on survival outcomes requires further exploration. Temel et al (2010) found that patients in the US with newly diagnosed metastatic non-small cell lung cancer who received early palliative care had an improved survival rate of two months. On examination of this trial by the NLCFN committee the palliative care interventions arguably are likely to reflect elements of the LCNS role in the UK.

The LCNS is also often involved in health promotion initiatives to raise awareness of the signs and symptoms of disease, and giving smoking cessation advice. LCNSs may work with local organisations such as schools as well to promote lung cancer awareness.

Multidisciplinary care
The LCNS supports the needs and wishes of patients in the multidisciplinary team (MDT). This advocacy role is especially important because of the number of healthcare professionals involved in decision making about diagnosis and treatment. It is common for patients to be contacted by the LCNS by telephone after the MDT discussion and guidance has been published to help LCNSs communicate these decisions (NLCFN 2009).

The diagnostic process has become more challenging with the development of new techniques and increasing treatment modalities (National Institute for Health and Care Excellence (NICE) 2011). The emergence of highly specialised treatments has added another dimension to the options available for patients, for example, stereotactic body radiotherapy for early stage lung cancers and stereotactic radiosurgery for brain metastases.

Co-ordination of these complex treatment pathways, which may also involve the conventional treatments of chemotherapy, radiotherapy and thoracic surgery, will usually be undertaken by the LCNS. Research into complex treatment decisions for patients with advanced lung cancer showed that LCNSs supported decision making and were seen as trusted sources of information (Thornton et al 2011).

Pre-diagnosis
LCNSs are involved in complex activity pre-diagnosis by providing information, co-ordinating tests, communicating with other healthcare professionals and supporting symptom management, including prescribing (White 2013). This activity occurs mostly in dedicated clinics or for inpatients when there is a high level of suspicion of lung cancer. The UK Lung Cancer Coalition (2012) recommends that LCNSs should be involved in pre-diagnosis care of all suspected lung cancer patients from the point of detailed investigations in secondary care.

Diagnosis
The NICE (2011) guideline states that an LCNS should be present at diagnosis. The psychological effect of diagnosis on patients and carers often requires special attention and it is important that patients are offered a holistic, co-ordinated and MDT approach to care (RCLCF 2011).

Once patients have been informed that they have suspected lung cancer, further tests and investigations are required. The working diagnosis is usually delivered by a respiratory physician, but can on occasions be given by an LCNS, who outlines the additional investigations required and the management plan.

The information provided to patients can be complex and the pathway can change as test results materialise. If patients are known to an LCNS they can be given the information by telephone. However, this may create anxiety for patients and it can be challenging for the LCNS to provide the information with sensitivity (NLCFN 2009). Good practice would suggest negotiating with patients about how they would like information imparted at the various steps of the pathway so they can consent for this to happen. Such an approach can build trust between patients, LCNSs and MDTs, which may also help with decision making when it comes to discussing treatment.

For most patients there will be a period of time from being told about the suspicion of disease to seeing a specialist to discuss treatment options. During this time, the LCNS is well placed to provide support and explain the diagnosis, potential treatment options, symptom management interventions and a follow-up plan from the initial consultation.

The LCNS should have the ability to triage the patient to the correct specialist, whether
The LCNS can also discuss referral for additional nursing and social care, benefits advice and palliative care if required.

The National Lung Cancer Audit for 2011 found that 55 per cent of patients were seen by an LCNS at diagnosis (HSCIC 2012). Although this represents an increase from 19 per cent in 2007 (HSCIC 2013) (Figure 1), it also means that 45 per cent of patients did not have the support of an LCNS at diagnosis, which is of great concern.

Treatment
Latest figures from the National Lung Cancer Audit for 2011 indicate that, although active treatment rates are increasing, there remain variations in the number of patients offered active treatment. In 2011, 60 per cent of patients received active treatment (HSCIC 2012), compared with under 50 per cent in 2005 (HSCIC 2013). The audit also found that 65 per cent of patients seen by an LCNS went on to receive active treatment, compared with 29 per cent who did not see an LCNS (Figure 2, page 20). Although not showing a causal link between LCNS input and having active treatment, the data are compelling.

When considering this correlation LCNSs can affect treatment uptake in a range of ways. Providing information at diagnosis about potential treatment options, including clinical trials, could help patients make an informed decision by the time they see the oncologist or thoracic surgeon. For patients with advanced disease, LCNSs have the opportunity to intervene with symptom control before a consultation with the oncologist, which may improve symptoms and fitness levels, and make it more likely that patients are offered active treatment.

LCNSs also provide formal follow up in treatment pathways. One example is an LCNS-led clinic for patients receiving erlotinib (NLCFN/RCLCF 2013). Consensus guidelines (McPhelim et al 2011) have also been developed to aid this approach to care, with many MDTs considering new models of service delivery in light of the skills and knowledge of the LCNS to deliver these services.

There are other examples of LCNS-led services. A thoracic surgical rehabilitation programme (NHS Improvement 2013) has helped to reduce post-surgical complications from 19 per cent to 11 per cent, with a decrease in intensive care admission and hospital readmission rates in the intervention group compared with the control group. The LCNS recruited patients to the programme and supported them throughout.

The Scottish Intercollegiate Guidelines Network (2005) also recommends that breathlessness clinics led by nurses or physiotherapists should be made available to all lung cancer patients. Nurse-led breathlessness clinics can lead to improvements in breathlessness, functional ability and physical...

The focus of all these initiatives is to improve quality of life and educate patients about their illness and treatment.

**Follow up**

The NICE (2011) guideline recommends that there needs to be a consistent and informed approach to follow up, particularly in terms of the timing of appointments and access to specialists. However, Beckett et al (2011) found large variations in follow-up practice among UK oncologists. The NLCFN’s (2010) nurse-led follow-up guidelines state that patients should have a discussion about the role and function of follow up, which usually includes an assessment in the outpatient clinic but can also be by telephone with the most appropriate specialist.

LCNS follow up is a recommendation in the NICE (2011) guideline, which stipulates that teams should offer protocol-driven follow up led by an LCNS if patients have a life expectancy of more than three months. The NLCFN (2010) nurse-led follow-up guidelines help LCNSs and MDTs to deliver this service.

Compared with conventional medical follow up of patients with lung cancer, nurse-led follow up has been shown to reduce medical consultations, improve patient satisfaction and increase the number of patients dying at home rather than elsewhere (Moore et al 2002).

NICE (2011) also recommends that patients know how to contact the LCNS involved in their care between scheduled hospital visits. Access to the LCNS is crucial as it is difficult to predict what may occur for each patient and at what time, for example, the development of brain metastasis or spinal cord compression.

**Last year of life and end of life care**

Cancer Research UK (2013c) statistics showed that 35 per cent of patients presented with stage IV advanced disease at diagnosis in England and Wales in 2011. Detailed and practical guidance on supportive and palliative care interventions for patients with advanced lung cancer or mesothelioma in the last year of life is provided by the NLCFN (2012). The LCNS can co-ordinate any necessary interventions and offer expert advice and guidance to hospital and community teams.

When they are informed that they are approaching the end of life, patients may be seen in the outpatient clinic or as an inpatient. With the range of services that can be provided by primary and secondary care, co-ordination needs to be prioritised to prevent duplication or misunderstanding. The LCNS should be central to this process and proactive.

![Figure 2](Health and Social Care Information Centre 2012, National Lung Cancer Forum for Nurses and the Roy Castle Lung Cancer Foundation 2013)
in communicating the plan of care with the various teams. ‘Fast track’ care co-ordination (DH 2012b) can be initiated. Liaison with the palliative care team is common; some LCNS roles even include a palliative care specialism.

**Survivorship**

The LCNS is also in the best position to co-ordinate a structured assessment of patients’ needs and plan of future care once treatment is completed. Patients should be given a treatment summary documenting the care provided and highlighting signs and symptoms of recurrence and the consequences of treatment (DH 2013).

If problems occur patients should know how to contact the team for advice, and this will usually involve contacting the LCNS. Many LCNSs also run support groups which, while time-consuming, can be a great source of ongoing mutual support for patients and carers given their complex needs (NLCFN/RCLCF 2013).

**Cost savings**

Evidence shows that LCNSs can contribute to cost savings for the NHS. White (2010) provides examples of good practice initiatives by LCNSs and MDTs in reducing length of inpatient stay, which are supported by the DH (2010).

For example, the Sherwood Forest Hospitals NHS Foundation Trust reduced the average length of stay for lung cancer patients by 25 per cent (White 2010). A recurring admission patient alert system was developed where lung cancer nurse specialists were issued with Blackberry handheld devices that gave an instant alert of admission. The success of this approach was implemented across the trust and won an award at the 2007 Medical Futures Innovation Awards.

A study in Manchester (NCAT 2010b) found that service improvements along the cancer pathway led by lung and breast CNSs could save about 10 per cent of cancer expenditure. In another example, LCNSs in London delegated administrative tasks and adopted a proactive case management approach, which resulted in a drop in admissions for non-acute problems from four to 0.3 a month and represented a significant return on investment in nurse posts (Baxter and Leary 2011).

Macmillan Cancer Support (2011) reported that CNSs have been shown to represent good value for money by reducing the number of emergency admissions, length of hospital stay, number of follow-up appointments and number of medical consultations, and by providing support to enable people to be cared for and die in their place of choice.

The case studies highlighted in the NLCFN/RCLCF (2013) report also show that LCNSs can increase productivity and efficiency by managing treatment side effects and symptoms and preventing costly unplanned hospital admissions. Nurse-led services also free up consultants’ time and empower patients to self-manage some symptoms, making additional efficiency savings.

Despite these improvements, evidence is emerging that LCNSs are not always able to fulfil their role because of hospital pressures on other services. A survey undertaken by the NLCFN (2011) found that 10 per cent of LCNSs were being asked to work on wards to ease staffing pressures. LCNSs potentially open up bed occupancy, so it is not cost effective for them to work on wards. The goodwill of LCNSs in working overtime unpaid has been reported by Leary et al (2008), who found that on average LCNSs worked an additional 6.5 hours a week. The Royal College of Nursing (2010) recognised that specialist nursing posts often come under threat during times of financial austerity despite evidence that patients value the services they offer.

**Implications for practice**

The NLCFN/RCLFC (2013) report provides insights into the role and effect of the LCNS in the disease pathway. The report aims to help all LCNSs show evidence for their role and it can also be
used by other CNSs working in similar cancer pathways. The evidence for the influence of CNSs on patient experience and on treatment uptake is particularly compelling.

Conclusion
This article has examined the complex and varied roles of LCNs and their contribution to the delivery of high quality care across all stages of the patient pathway. LCNs’ part in improved NHS productivity and efficiency can also be demonstrated, which poses a challenge to all lung cancer teams to identify how they can develop LCNs services.

The figure of just over half of patients with lung cancer having an LCN present at diagnosis (HSCIC 2012) needs to increase substantially, while LCNs workload will increase with the advent of new therapies for lung cancer that could improve survival rates. Policymakers, commissioners, providers and clinicians should plan for expanding the LCNs workforce to deliver the levels of care needed.

References
National Cancer Action Team (2010b) Lung Cancer Facts and Figures. tinyurl.com/netj3wo (Last accessed: October 3 2013.)