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

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A B S T R A C T

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 into 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.

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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 can be productive not only in terms of quality but also in terms of efficiency for example the avoidance of unnecessary admission to an acute inpatient unit (Quinn, 2011; Baxter and Leary, 2011). However it is likely that this activity can only happen when the specialist nurse can manage the caseload proactively (NCAT, 2013) and not reactively (for example only responding to crisis). The work is multifunctional and complex (Leary et al., 2008a) covering areas such as managing care, complex symptom control and identifying, alleviating and or referring issues that are psychological in nature such as distress and uncertainty, as in lung cancer there is often an unmet need (Ugalde et al., 2012).

The aim of this study was to examine, 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

As part a of larger study, one hundred members of National Lung Cancer Forum for Nurses (NLCFN) was sent an on-line questionnaire to ask about workload using Survey Monkey (Survey Monkey 2012). This covered the four countries of the UK. This consisted of questions on size of caseload, which parts of the patients' pathway they were either involved in or managed, how much unpaid overtime they worked and what specialist nursing care they felt unable to complete for their patients against best practice standards (Cancer Action Team, 2007; NICE, 2011; Roy Castle and NLCFN, 2013). They were also given the option to use a free text box to elicit what they thought were the primary reasons for not being able to complete these areas of care or barriers to providing holistic services.

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 at times when more nursing vigilance is required such as disease progression or starting new therapies, performing and acting on a holistic needs assessment (Cancer Action Team, 2007), meeting level two psychological needs including referral onwards (NICE, 2004), meeting social and financial needs, meeting symptom control and disease management needs and fully assessing and meeting information needs of the patient and family.

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) 61 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