



A systematic review of supportive care needs of people living with lung cancer



Roma Maguire^{a,*}, Constantina Papadopoulou^a, Grigorios Kotronoulas^a,
Mhairi F. Simpson^b, John McPhelim^c, Lynn Irvine^d

^a School of Nursing & Midwifery, University of Dundee, 11 Airlie Place, Dundee DD1 4HJ, UK

^b Wishaw General Hospital, NHS Lanarkshire, Netherton Street, Wishaw ML6 0JS, UK

^c Hairmyres Hospital, NHS Lanarkshire, Eaglesham Road, East Kilbride G75 8RG, UK

^d David Matthews Building, Monklands Hospital, NHS Lanarkshire, Monkscourt Avenue, Airdrie ML6 0JS, UK

A B S T R A C T

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Background and purpose: Supportive care for people living with a diagnosis of lung cancer is paramount. The purpose of this systematic review was to determine the supportive care needs of people with lung cancer, and explore trends and gaps in the assessment of these needs emerging from this literature.

Methods: Through use of a wide range “free text” terms, a systematic search of five electronic databases (Medline, CINAHL, EMBASE, PsychINFO and BNI) was carried out for the period between January 2000 and September 2012. Two validated scoring systems were used to appraise eligible studies for methodological quality and level of evidence.

Results: Based on pre-specified selection criteria, 59 articles (25 of quantitative methodology; 34 of qualitative methodology) reporting on 53 studies were retrieved and considered for further analysis. Overall, studies were of acceptable methodological quality. A wide spectrum of health care needs was evident among people with lung cancer. These needs were classified into nine domains: physical; daily living; psychological/emotional; spiritual/existential; informational; practical; patient–clinician communication; social and family-related; and cognitive. Daily living, practical, and cognitive needs were given less attention in this literature.

Conclusions: People with lung cancer have a complex array of supportive care needs that impact on various life aspects. Yet, our knowledge still remains fragmentary. Embarking on new longitudinal exploratory studies and well-designed clinical trials is therefore strongly encouraged. The use of patient reported outcome measures as a clinical intervention tool may be viewed as a means of identifying and managing unmet needs in this patient population.

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Introduction

Lung cancer remains the most common cause of cancer related death, accounting for approximately 20% of the total cancer mortality (Ferlay et al., 2007). Most people with lung cancer experience a rapid and fatal course of illness (Fitch and Steele, 2010), and five year survival rates remain poor with only 10.9% of people with lung cancer living 5 years or more (Verdecchia et al., 2007). Such poor survival rates have been attributed to problems in the early detection of the disease that result in the majority of patients presenting in the

advanced stages, where the provision of treatments with curative intent is prevented (Corner et al., 2005). Supportive care is therefore paramount in this patient group (Li and Girgis, 2006).

Supportive care can be viewed as a patient-centred approach to identifying and effectively responding to a spectrum of patient care needs (Lam et al., 2011; Rittenberg et al., 2010). Supportive care needs (SCNs) have been defined as requirements for patient care pertinent to the management of symptoms and side effects, enablement of adaption and coping, optimisation of understanding and informed decision-making, and minimisation of functional deficits (Ream et al., 2008). Identifying and addressing such needs can well prevent patient distress, poor quality of life, and dissatisfaction with care (Sanders et al., 2010), as well as resultant increases in health care utilisation and costs (Brown et al., 2001).

Research relating to the SCNs of people with lung cancer has shown a constant increase over the past two decades (Dale and

* Corresponding author. Tel.: +44 (0) 1382 384965; fax: +44 (0) 1382 388533.

E-mail addresses: r.z.maguire@dundee.ac.uk (R. Maguire), c.z.papadopoulou@dundee.ac.uk (C. Papadopoulou), g.kotronoulas@dundee.ac.uk (G. Kotronoulas), Mhairi.Simpson@lanarkshire.scot.nhs.uk (M.F. Simpson), John.McPhelim@lanarkshire.scot.nhs.uk (J. McPhelim), Lynn.Irvine@lanarkshire.scot.nhs.uk (L. Irvine).

Johnston, 2011). However, to improve the quality of care provided, it is paramount that patient needs in this context are clearly understood. The purpose of the present systematic review is to gather current knowledge regarding the experiences and SCNs of people living with a diagnosis of lung cancer, as well as explore trends and gaps in the assessment of these needs emerging from this literature. The goal is to establish a knowledge base that can inform selection of the most appropriate patient-reported outcome measures (PROMs) for use in this population. Among others, PROMs can assist patients in communicating their needs and concerns, and consequently improve the quality of care provided (Fiscella et al., 2011; Lohr and Zebrack, 2009). However, this can only be achieved when the “right” PROM is selected based on patients’ perspectives of meaningfulness and priority (Lohr and Zebrack, 2009).

Methods

Search strategy

A systematic search of five electronic databases (Medline, CINAHL, EMBASE, PsychINFO, and British Nursing Index) was carried out for the period between January 2000 and November 2010. The search began on 1st November 2010, and concluded on 30th November 2010. In order to keep our review up-to-date with research being conducted, the search was re-run between 26th and 30th September 2012 to identify new studies published until the first week of September 2012. Aggregated results from both searches are reported here.

We initially developed our search strategy and subsequently revised it through an iterative process that involved three members of the research team. This strategy used a wide range of free text terms combined with subject headings that included the following:

- Lung cancer or lung neoplasms (MeSH terms)
- AND Needs assessment (support\$ care, patient care, care need\$, unmet need\$, support\$, palliative care, patient need\$, and need\$ asses\$).

In the next step, two search strings were implemented to separately identify published studies using a quantitative or qualitative methodology. The reference lists of retrieved studies were also examined for any studies that may have been overlooked. Additional literature was sought through use of the search engine Google Scholar to locate relevant publications using the aforementioned terms. This systematic review was planned and conducted according to published guidelines for reporting systematic reviews and meta-analyses (Moher et al., 2009).

Study eligibility criteria

Studies were eligible if they were written in the English language; were conducted with adult patients (>18 years of age); were published as original articles in peer-reviewed journals; and used a quantitative and/or a qualitative methodology reporting on the SCNs of people with lung cancer receiving a diagnosis of lung cancer or receiving/having recently received anticancer treatment or palliative care. Studies were excluded if SCNs and concerns were not reported and discussed (including questionnaire development studies); and had been conducted with patients with mixed cancer diagnoses (except when separate groups analyses were reported), or with survivors (greater than two years after diagnosis) of lung cancer or individuals receiving rehabilitative care as their health care needs could differ from those of people closer to diagnosis or with more advanced disease.

Article selection

Two members of the search team independently screened the retrieved articles for eligibility, following a two-step process (Fig. 1). In the first step, articles were selected based on titles and abstracts using the afore-mentioned eligibility criteria. In the second step, full texts were reviewed based on the same criteria. Disagreements were resolved by consensus following discussion with the lead author.

Quality appraisal and level of evidence

Reporting of studies was appraised via use of a validated scoring system for the systematic appraisal of empirical studies with varied methodologies (Hawker et al., 2002). Each study component (total of ten) of the full text paper was given a quality score ranging from 4 (good) to 1 (very poor), which generated a maximum potential score of 40. However, no studies were excluded on the grounds of quality. Clarification of the different methodological components was aided through use of the STROBE statement checklist for reports of observational studies (Vandenbroucke et al., 2007). In addition, to promote an evidence-type approach, a validated grading hierarchy was used to assess the level of evidence presented according to the type and quality of research using the evidence categories employed by the UK Department of Health in the National Service Frameworks (Department of Health, 2001).

The selected articles were independently appraised by two of the authors. Independent scores were cross-checked for consistency, and any differences were resolved within the team. Inter-rater agreement was also examined through calculation of intraclass correlation coefficients (ICC) and Cohen’s kappa statistic for the two appraisal datasets. Results were interpreted according to established benchmarks for assessing agreement between raters (Landis and Koch, 1977), namely poor (<0), slight (0.0–0.20), fair (0.21–0.40), moderate (0.41–0.60), substantial (0.61–0.80), and almost perfect (0.81–1.00). Overall, substantial agreement was reached on the quality appraisal scores (ICC = 0.80; 95% CI 0.69–0.88), whereas moderate agreement was reached on the evidence scores (kappa = 0.69; $p < 0.001$).

Data extraction and analysis

Data extraction forms, specifically designed for this review, were completed for each one of the selected studies. Extracted information included citation details, setting, study design, participant characteristics, data collection and analyses, findings/outcomes, strengths and limitations, reviewer comments, as well as quality and level of evidence scores. Due to heterogeneity of the studies retrieved, findings were integrated using narrative synthesis. Frequency analyses of findings and study characteristics were performed, where applicable, using Microsoft® Excel spreadsheets.

Findings

Paper selection process

Of the 5547 citations identified fifty-nine (34 drawing on qualitative methods and 25 drawing on quantitative methods) articles reporting on 53 studies (31 and 22, respectively) met eligibility criteria, and were considered for further analysis (Fig. 1). A summary of the characteristics of the articles reviewed is provided in Tables 1 and 2 for quantitative and qualitative studies, respectively.

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