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Patient expectations and preferences for follow-up after treatment for lung cancer: A pilot study

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ABSTRACT

Introduction: There is no robust evidence to indicate the most appropriate models of follow-up care for patients who have completed treatment for lung cancer. This pilot study aimed to assess expectations and preferences for follow-up care in a sample of patients who had completed treatment for lung cancer.
Method: Thirty-one patients who had completed treatment for primary lung cancer were recruited. A 13 item self-report survey was developed to elicit patient's preferences and expectations for follow-up. Participants completed the developed survey and clinical and demographic variables were collected.
Results: Factors scored as *extremely important* by over 80% of respondents focused on care coordination: *Being able to see the same doctor or health care professional at each visit* (24/83%); *Knowing which doctor or nurse to contact if queries arise between follow-up appointments* (23/82%); and *Knowing the patient can book an appointment or contact a health care professional involved in their care regarding health concerns between visits* (25/89%). Patients were supportive of nurse-led follow-up when offered in the context of a model of shared care (21/78%).
Conclusion: This study offers new insight into the expectations and preferences for follow-up of patients with lung cancer, with participants indicated preference for intensive follow-up after the completion of treatment.

Introduction

Most patients diagnosed with lung cancer have a poor prognosis (Sura et al., 2008). As such, managing disease-related symptoms, side-effects of treatment and psychosocial sequelae are vital components of follow-up care in order to promote optimal quality of life (Muers et al., 1999). Both patients with lung cancer and their carers experience feelings of isolation and lack of certainty about where to get support and advice after completion of cancer treatment (Krishnasamy et al., 2007). These feelings occur in the context of ongoing health care needs which span requirements for surveillance for recurrence, treatment of long-term and late effects of cancer therapies and care to address psychosocial well-being (Lobchuk et al., 2006). Despite the complexity of the problems experienced by patients with lung cancer, clinical practice guidelines offer no clear recommendations about how and when follow-up care should be provided (National Health and Medical Research Council, 2004).

The ambiguity and uncertainty associated with follow-up care, however, is not just restricted to lung cancer patients. For cancer patients generally, the benefit of follow-up care in terms of detecting disease recurrence or promoting emotional well-being remains unclear (Leitch and Wilkinson, 1994; Loprinzi, 1995). Evidence to inform preferred model and provider of follow-up care is equivocal (Grunfeld et al., 1999; Holtedahl et al., 2005). Data from a randomised controlled trial to elicit the follow-up preferences of women with breast cancer found that satisfaction was higher with primary care follow-up versus specialist care (Grunfeld et al., 1999). In contrast, a study to assess preferences for follow-up amongst patients with lung cancer indicated clear preference for standard medical or nurse-led follow-up over GP follow-up (Cox et al., 2006). Deficiencies in communication across health care settings are known to impact the capacity to deliver streamlined follow-up. Delays in information exchange between specialists and primary care physicians and failure to schedule follow-up appointments impact efficacy and adequacy of follow-up care provision (Gandhi et al., 2000; Schoen et al., 2004). Many of these problems have been linked to overstressed primary care services, lack of computerised records or compatible information technology programs for sharing information within and across health care settings and lack

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of integrated models of care that enable care coordination (Bodenheimer, 2008). Despite this, there is growing pressure on health services to develop more cost efficient ways of delivering follow-up care (Wilson et al., 2006; Wein, 2008).

Limiting the capacity to develop improved models of follow-up care is a lack of empirical evidence about what patients want from follow-up and who they want it with (Wilson and Amir, 2008). Lack of clarity around the intent of follow-up care for different groups of cancer patients is also problematic. One response to the pressure to reform models of care provision, particularly in follow-up, has been the development of nurse and GP-led follow-up services (Moore et al., 2002; Beaver et al., 2006; Lobchuk et al., 2006; Cox et al., 2006). While evidence to indicate the effectiveness or acceptability of these new models of care is limited, a descriptive study of 72 patients with lung cancer indicated that both standard medical and nurse-led follow-up were rated as highly acceptable and preferable to GP-led or telephone follow-up (Cox et al., 2006). Patient acceptability of nurse-led follow-up was rated as “high” by 203 patients with lung cancer in a randomised controlled trial comparing nurse-led care and conventional medical follow-up (Moore et al., 2002). Patients who received nurse-led follow-up also reported significantly less severe breathlessness ($p = 0.03$) and better emotional functioning ($p = 0.05$) than participants who received usual care. Further research is needed to test alternative models of care in order to ensure that patients with lung cancer receive appropriate and timely follow-up services.

The aim of this pilot study was to assess lung cancer patients' preferences and expectations of follow-up care after treatment completion in order to generate new insights amenable to development and testing in future studies.

Materials and methods

This project was approved by the local Human Research Ethics Committee.

Survey development

A review of the literature was conducted to identify key themes related to patient follow-up after lung cancer treatment. An electronic search of English language papers published between 1996 and 2007 was undertaken using the CINAHL, Medline, Web of Science and the Cochrane databases. Search terms included: lung cancer treatment, follow-up, surveillance, post treatment, patient choice, patient preference, survivorship. No limits were placed on study design. Papers that made reference to follow-up of patients post completion of treatment for lung cancer were utilised to construct themes for the questionnaire. Two members of the project team categorised themes into domains of follow-up to generate survey questions to identify preferences and expectations for follow-up within each of the domains identified. The following domains were identified: 1) timing of first follow-up appointment after treatment completion; 2) frequency of follow-up appointments in the first 12 months; 3) discipline of health professional who provides the follow-up; 4) types of care provided within the context of follow-up; and 5) coordination of follow-up care. The project team developed a 13-item, self-report questionnaire based on these themes. It was reviewed for face validity, comprehensiveness and ease of comprehension by a multidisciplinary expert panel which consisted of health professionals from the disciplines of medical oncology, radiation oncology, surgical oncology, nursing, social work and physiotherapy. No changes were made as a result of expert review.

Setting

A multidisciplinary lung clinic within a specialist cancer centre.

Participants

Ambulatory care patients with a primary diagnosis of lung cancer, irrespective of tumour type, who had completed surgical, radiotherapy or chemotherapy treatment for lung cancer and had ECOG status 3 or less were eligible to participate. Patients with a cognitive impairment as defined by the lung cancer clinical nurse coordinator or oncologist responsible for their care; patients who had an additional course of treatment planned; non English speaking patients; and patients participating in other supportive care research studies were excluded.

Procedure

A research assistant screened clinic lists and consulted with the lung clinical nurse coordinator to identify eligible patients. Potential participants were approached within two weeks of their last clinic appointment before treatment completion. Surgical patients who were planned for follow-up, but were an in-patient at the time of completing treatment, were not approached until they had been discharged. Patients who provided written consent to participate were asked to complete a survey while at the hospital. If there was insufficient time for the patient to complete the survey whilst at the hospital, a reply paid envelope was provided and patients were asked to complete the questionnaire at home and return it within two weeks. This time frame ensured that patients completed the questionnaire before their fist follow-up appointment. The research assistant telephoned patients to remind them to return the survey as necessary.

Measures

- *Demographic and disease variables.* Data relating to age, marital status, disease stage, treatments received, co-morbidities, diagnostic group, intent of treatment, gender, social situation (for example, living alone, distance from treating hospital), smoking history and ECOG status were obtained from hospital records. Patients were asked to provide self-report data on educational and employment status.
- *Preferences and expectations of follow-up.* The 13 item self-report survey to assess patient expectations and preferences for follow-up with regard to timing of first follow-up (2 items, e.g., *following completion of your lung cancer treatment how soon do you expect to have your first follow-up appointment?*); frequency of follow-up in the first 12 months of treatment completion (2 items, e.g., *in the first year after finishing treatment, how often would you like to have follow-up appointments?*); discipline of provider of follow-up (3 items); content of follow-up (4 items) and coordination of follow-up care (2 items). The grading scale was not consistent across the questionnaire and varied with the items.

Data analyses

Descriptive statistics including means, frequencies and percentages were calculated to summarise the results of the 13-item survey.