



NURSE LED FOLLOW-UP GUIDELINES

Produced by National Lung Cancer Forum for Nurses

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INTRODUCTION

Most lung cancer patients are offered some form of follow-up after treatment, although the effectiveness of this is the subject of debate. The NICE lung cancer guidelines (1) note that there are no systematic reviews of best practice, but that there is one randomised controlled trial on nurse led follow-up. NICE recommends that

After completion of their treatment, patients with an expectation of life greater than three months should have access to protocol controlled nurse led follow-up as an option.

There is increasing interest in the most appropriate mode of follow-up for lung cancer patients who have completed their treatment, and with this in mind, these guidelines have been written to help Lung Cancer Clinical Nurse Specialist (CNS) to implement nurse led follow-up.

AIM AND OBJECTIVES

Aim

- to provide National Good Practice Guidelines for Developing Nurse Led Follow-up for Lung Cancer Patients.

Objectives

- to improve follow-up of patients with lung cancer;
- to provide a national standard of care;
- to provide guidelines to assist Lung Cancer CNS's in setting up nurse led follow-up.

REVIEW OF THE CURRENT EVIDENCE

Follow-up after curative-intent therapy

Colice et al (2) recommend the development of various follow-up programs for lung cancer patients depending on the original diagnosis and treatment intent. Follow-up for complications should be performed by the specialist responsible for the curative intent therapy and should last 3-6 months. Following this a standard surveillance program is recommended with periodic visits, chest imaging studies, patient education regarding symptom recognition and smoking cessation.

Detection of Recurrent Disease/Metastases

Younes et al (3) found that the disease-free interval was not influenced by the pattern of follow-up and that metastatic diseases were usually detected on the basis of symptoms rather than routine tests.

Holistic Follow-up

An important component of post-treatment cancer care is physical, social and psychological rehabilitation, and a busy conventional clinic staffed only by an oncologist is unlikely to provide this (4).

Patients with lung cancer have been shown to experience greater levels of unmet psychological, social and economic needs, in addition experiencing more complex, sometimes intractable symptoms, than other cancer groups (5). Saunders et al (6) suggest that for lung cancer there is a lack of evidence on which to recommend a general policy for patient follow-up, even though this constitutes an important part of lung cancer management. Follow-up clinic appointments need to be responsive to individual needs and concerns, with equal emphasis on the psychosocial aspects of lung cancer.

Patients' Wishes/Role of Lung Cancer CNS

The Macmillan Cancer Support principles of people-centred care document (7) found that patients having follow-up after treatment want reassurance and guidance, with a planned approach to their care, to ensure that the services they need are in place and that they can access on-going support for themselves and their families. In lung cancer care, the key components of follow-up have been highlighted in the integrated *Lung Cancer Nursing: Good Practice Guide (2004)* (8) as being support, information, communication, open access, nursing assessment, patient advocacy, multidisciplinary team membership and co-ordinating care. These are the core elements of the Lung Cancer CNS's role.

THE EVIDENCE FOR NURSING FOLLOW-UP

According to the NICE guidelines, only one randomised controlled trial of nurse led follow-up for lung cancer patients appears in the literature. This study of nurse led follow-up (9) versus conventional medical follow-up in managing patients with lung cancer suggested that, despite substantial evidence that intensive follow-up after cancer treatment may not lead to improvements in survival or quality of life, patients were routinely seen in outpatient clinics.

Most patients were extremely positive about their experiences under the nurse led follow-up system and all requested that their care should continue to be managed this way. Nurse led follow-up was acceptable both to lung cancer patients and GPs, and led to positive outcomes.

The controlled trial by Moore's group in 2002 also indicated that nurse led initiatives can be used to reconfigure care to make it more responsive to individual needs, increase patient satisfaction and reduce the burden of hospital visits and investigations. When lung cancer patients were asked whether their needs were met (10), three main concerns were identified:

- the future related to their disease;
- their families;
- the illness itself.

This reinforces the notion that the complex psychological needs of lung cancer patients, more than the physical symptoms, are based on a continued concern for their own mortality, a sense of vulnerability, uncertainty and concern for their quality of life and their family (11). However, psychosocial concerns were also less likely to be mentioned by patients during a medical consultation. This may be because:

- their concerns may not be relevant;
- doctors and nurses may be reluctant to elicit concerns knowing that they have insufficient time to deal with the issues raised;
- clinics can be noisy and not the best place to facilitate discussion (12).

The Yorkshire Lung Cancer Nurse Forum (YLCNF) defined the Lung Cancer CNS support and follow-up as an assessment of the patient's ongoing physical, psychosocial, spiritual and surveillance care throughout their disease trajectory. The YLCNF also worked on creating a protocol that could be incorporated into the current lung cancer service pathway (13). The YLCNF also felt that having a written protocol would help to allay any concerns within the lung cancer MDT, whether from other specialist nurses, respiratory medicine, clinical and medical oncology, surgery or palliative care. The objectives of the protocol were to:

- provide additional choice to patients with lung cancer in the form of Lung Cancer CNS support and follow up, i.e. by phone, home visit or in the clinic;
- provide evidence-based flowcharts and guidelines for symptom management for the Lung Cancer CNS;
- evaluate the impact of the protocol.

The YLCNF explored the introduction of a nurse led follow-up services and felt that the service would:

- provide the complex elements of care that matter to those affected by lung cancer;
- develop the role of the Lung Cancer CNS;
- develop the service to be responsive in meeting the needs of patients and carers;
- offer consultancy to other health professionals throughout the patient pathway.

The development of a nurse led follow-up protocol by the Yorkshire Cancer Network should help other Lung Cancer CNSs who are struggling to set up nurse led initiatives. The protocol is a good resource, which can be used by any lung cancer MDT and it can be adapted to local practice. The protocol focused on meeting the needs of the lung cancer population and it allows the lung MDTs within hospital Trusts to be more flexible and responsive to patients in accordance with the recommendations made in the NICE guidance.

RECOMMENDATIONS TO IMPLEMENT THE GUIDELINES

- there should be local guidelines for referral to nurse led follow-up (14);
- it should be decided by the MDT which patients can be referred for nurse led follow-up; for example, following radiotherapy, chemotherapy or surgery, or at the time when supportive care is recommended;
- assessment of patient needs should take place;
- activity should be recorded, including audit;
- patient information should be available;
- there should be easy access back to the MDT;
- there should be good communication pathways to respiratory and oncology consultants, as well as to GPs.

A MODEL OF FOLLOW-UP FROM THE YORKSHIRE CANCER NETWORK

The Lung Cancer CNS support and follow-up protocol may be discussed with the patient by the clinician or the Lung Cancer CNS either

- when the patient asks about follow-up;
- at the first follow-up visit to the clinic following treatment;
- at the time when supportive care is recommended.

A patient information sheet or leaflet will be given to the patient to outline the support and follow-up procedure.

In the event of the patient preferring conventional follow-up, this will continue.

If the patient expresses a preference for Lung Cancer CNS follow-up, a discussion should take place between the physician and the patient and the next follow-up intervention agreed. The Lung Cancer CNS should be informed and then discuss with the patient the mode and timing of the follow-up assessment.

Depending on the circumstances, particularly patient preference, the assessment can be by:

- telephone;
- home visit;
- clinic visit;
- a combination of the above; and
- can involve other health professionals within the multi-disciplinary team.

The first, and comprehensive, assessment by the Lung Cancer CNS is undertaken at the first follow-up appointment.

A subsequent assessment is made at each subsequent appointment.

A recording of the assessment should be made in the patient's notes or records. Letters should be sent to the appropriate consultants and primary care team.

Patients should be offered a copy of the letter.

Patients should be informed that there is easy access back to the medical team if requested.

TROUBLESHOOTING GUIDE

Problems that may arise

Suggestions

Clinicians do not show interest

Discuss the evidence given in these guidelines in MDT
Involve User/Support Groups and use their support/influence
Find an ally e.g. Lead Clinician

Lack of clinic space

If you are going to be following up patients who would previously have been seen by the oncologist, the oncologist's clinic time will be reduced, thus leaving space for your clinic
Consider telephone follow-up if appropriate

Lack of time

You will probably only be given a 1-2 hour clinic slot. However, during this time you are able to give 3-6 patients 'quality time' which should result in your now having to spend far less time than previously supporting these patients on the telephone
Potentially timesaving: organising time more effectively; reducing patient visits to hospital; being proactive in early management of symptoms

Missing new referrals

Liase with respiratory physicians: see if clinics can be restructured with new patients coming early and follow-ups coming later

Lack of secretarial support

If you were not seeing these patients, the oncologist would be; therefore asking the oncology secretary to type your letters, you are not giving him/her any additional work (NB secretarial support is vital, so this should be agreed at the outset)

Lack of patients

This is unlikely if you have agreed referral criteria at MDT
Explore reasons for lack of referrals e.g. discuss at MDT

Patients too unwell

Refer to community services

Becoming a 'dumping ground'

Be prepared to say 'no' when clinicians try to refer patients who do not meet referral criteria

Patients have multiple co-morbidities

As long as these are stable, this is OK
Need to have a mechanism for getting patient seen by appropriate hospital physician

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