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**Nurse specialist led follow-up in lung cancer: The
experience of developing and delivering a new
model of care**

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Summary

Data from an earlier paper reporting on a study comparing conventional medical follow-up with nurse specialist follow-up of patients with lung cancer demonstrated that follow-up by nurse specialists is safe, effective and can lead to greater levels of patient satisfaction. The process and experience of developing a nurse specialist role in lung cancer follow-up care has not yet been described. The aims of this paper are to describe the preparation and development of a model of nurse led follow-up care, identify key nursing interventions provided within nurse led follow-up care and provide insights into the experiences of nurse specialists providing follow-up care. Data were collected from nurse specialists' patient case-records and from meetings held with the study team. Semi-structured interviews were conducted with the nurse

specialists providing follow-up care and the study coordinators. The nature of the nursing role in lung cancer follow-up care is described. In addition, four themes relating to the process of developing a nurse led follow-up role are identified. These are: 'training', 'becoming credible', 'emotional burden' and 'making a difference'. Managing follow-up care for patients with lung cancer can be rewarding for nurse specialists. However, it can also be emotionally demanding. Training and support for such roles is vital and requires further in-depth research.

Zusammenfassung

Daten aus einer älteren Publikation, in der über eine Studie berichtet wurde, bei der ein Vergleich zwischen einem konventionellen ärztlichen Follow-up und einer Nachbetreuung von Lungenkrebspatienten durch spezialisierte Krankenpflegekräfte stattfand, zeigen, dass eine Nachbetreuung durch eine spezialisierte Krankenpflegekraft sicher und wirksam ist und bei den betreuten Patienten zu größerer Zufriedenheit führen kann. Bisher existieren noch keine Berichte über die Entwicklung von Prozeduren für die Nachbetreuung von Lungenkrebspatienten durch spezialisierte Krankenpflegekräfte. Das Ziel dieses Artikel bestand darin, die Vorbereitung und Entwicklung eines Modells für ein Follow-up zu beschreiben, das hauptsächlich von Krankenpflegekräften durchgeführt wird, die wichtigsten pflegerischen Interventionen innerhalb einer hauptsächlich

von Krankenpflegekräften wahrgenommenen Nachbetreuung zu identifizieren und über die Erfahrungen spezialisierter Krankenpflegekräfte zu berichten, welche die Nachbetreuung durchführen. Die erhobenen Daten stammten aus den Patientenakten der spezialisierten Krankenpflegekräfte sowie aus Meetings, die mit dem Studienteam abgehalten wurden. In semistrukturierten Interviews wurden spezialisierte Krankenpflegekräfte sowie die Studienkoordinatoren befragt. Es werden die Eigenschaften der Tätigkeit einer Krankenpflegekraft bei der Betreuung von Patienten mit Lungenkrebs beschrieben. Ferner werden vier Aspekte des Prozesses der Entwicklung eines Modells für ein Follow-up identifiziert, das hauptsächlich von Krankenpflegekräften durchgeführt wird: „Training“, „glaubwürdig werden“, „emotionale Belastung“ und „einen Unterschied ausmachen“. Die Durchführung einer Nachbetreuung von Patienten mit Lungenkrebs kann sich für spezialisierte Krankenpflegekräfte als eine dankbare Tätigkeit erweisen. Eine solche Tätigkeit kann jedoch emotional belastend sein. Ausbildung und Unterstützung der Krankenpflegekräfte sind von entscheidender Bedeutung und müssen in weiteren Forschungsprojekten eingehend untersucht werden.

Keywords: Lung Cancer; Nursing roles

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Introduction

Recent Government guidelines for England and Wales recommend that follow-up care managed by nurse specialists should be offered to patients with lung cancer who have completed treatment (National Institute for Clinical Excellence (NICE), 2005). The evidence for this recommendation is based on findings from a randomised controlled trial recommendation is based on findings from a randomised controlled trial conducted by the authors which established that nurse specialist led follow-up care for patients with lung cancer is safe, effective and can lead to greater levels of patient satisfaction (Corner et al., 2000).

The main statistical findings from this study have been reported in an earlier paper (Moore et al., 2002), but the nurses' experiences of developing and delivering the new model of care have not been described. This paper draws on evidence from patient case-notes completed by the nurse specialists undertaking follow-up, interviews with the nurse specialists and study co-ordinators, and transcripts from meetings with the study team to describe the rationale for and nature of the nurse development phases of the nurse led follow-up model of care, identifies key nursing interventions provided within follow up-care and provides led model of follow-up care. It outlines the preparation and insights into the experiences of the nurse specialists delivering follow-up care. As alternative models of follow up care continue to develop in the UK and across Europe, it is important that nurses consider the full implications of new methods of care delivery. It is hoped this paper will highlight some of these issues and will provide specific guidance for nurse specialists responding to the recent NICE recommendations (2005).

Background

A new nursing role in the area of lung cancer follow-up care was conceived in the mid-1990s at a time of increased scrutiny of lung cancer services in the United Kingdom. Surveys and reports had recognised that care was fragmented (Standing Medical Advisory Committee, 1994), health professionals were over-pessimistic in their attitudes

towards lung cancer and its management (National Health Service Executive, 1998), and patients received little support from health care professionals despite the plethora of problems they experienced (Krishnasamy and Wilkie, 1999). Moreover, the rationale for routinely following up patients in busy hospital outpatient clinics was being questioned (Brada, 1995). Evidence from a number of studies had suggested that intensive follow-up for many patients with cancer did not lead to any improvement in survival or quality of life and was not cost-effective (GIVIO Investigators, 1996; Grunfeld et al., 1993; Kievit and Bruivels, 1995). More recent work demonstrates this debate continues (Collins et al., 2004; Smith, 2003).

Evidence at the time of the study also suggested that routine appointments were an inefficient method of detecting cancer recurrence and that patients themselves may be more likely to identify problems in between appointments (Grunfeld et al., 1993; Radford et al., 1997). The emphasis on disease surveillance in a busy outpatient clinic may be particularly inappropriate for patients with lung cancer, who experience significant physical and psychological morbidity and have a poor prognosis.

Against this background, Corner and colleagues proposed an alternative model of follow-up care for patients with lung cancer, led by cancer nurse specialists. Rather than being seen routinely by a doctor, patients who were stable on completion of treatment would be supported by nurse

specialists. The nurse specialists would be responsible for coordinating follow-up care and, depending on need, would provide information, emotional support, symptom management and referral to oncologists, palliative care teams, social care and/or primary care. Funding was secured from the National Health Service Research and Development Cancer Programme to develop and evaluate the alternative model of nurse led follow-up care at a specialist cancer hospital in South East England and three local district general hospitals. A randomised controlled trial comparing conventional medical follow-up with nurse led follow-up of patients with lung cancer was conducted from January 1997 to September 1999 (Moore et al., 2002). Ethical approval for the study was gained from each of the participating hospitals' ethical committees.

Development of an alternative model of follow-up care

An audit of patients' case-notes at the cancer hospital involved in the study revealed the existing model of follow-up care focussed primarily on disease surveillance and lacked:

- co-ordination
- consistency in terms of doctors seen
- adequate assessment of patients' symptom control, psychological and social needs, and

- referral to other health care professionals and support agencies for additional patient support.

This part of the study has been reported elsewhere (Moore et al., 1999).

It was agreed with medical staff that a more supportive nurse specialist led model of follow-up care could, for some patients, replace the costly hospital model currently in place. The nurse led follow-up model of care would be developed to ensure:

- safe monitoring of disease status
- continuity of care
- open access to advice and support in times of need
- equal emphasis on addressing the physical, psychological and social needs of patients with prompt referral to other health care professionals/support agencies as appropriate
- close liaison with primary care and palliative care teams, and
- support for carers.

It was anticipated that when patients were well, they would be monitored through structured telephone assessment, with rapid access to a nurse led or medical clinic when problems occurred. Nurse specialists would coordinate appointments and order necessary investigations at either the cancer

hospital or one of the local hospitals, so as to make better use of resources and reduce the number of unnecessary hospital trips for patients.

Although clinic space was scarce, at least one room was obtained for a nurse led clinic in each hospital. Clinics were held alongside other chest or lung cancer clinics, thus providing access to medical support where necessary, and an opportunity for multidisciplinary team working. Table 1 outlines the main features of the nurse led follow-up model of care.

Table 1.

Key aspects of nurse led follow-up care.

- Direct access to nurse specialists Monday–Friday; ‘open access’ clinics, telephone
- Telephone assessment clinic appointment 2 weeks after recruitment to nurse le
- Clinic assessment form to be completed at each clinic appointment or telephone
- Weekly ‘open access’ nursing clinics at the three study sites. Short notice (i.e. s
- Emphasis on rapid and comprehensive communication with GP and primary he
- Regular discussion with and referral to medical team on detection of any new sy
- Documentation of nurse-led clinic in notes, to GP, home care team/hospice if ap

Meetings were held with key nursing, medical and operational personnel to ensure all were adequately informed about the new model of care. Clinic templates and codes were set up for all nurse led clinics. An assessment tool (Fig. 1) and scoring system (Fig. 2) for the commonest

symptoms was developed and agreed with medical and nursing staff. These were based on existing tools developed by Regnard and Hockley (1995), Hollen et al. (2003) and the Oncology Nursing Society (1994).



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Figure 1. Lung clinic assessment form.



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Figure 2. Symptom scoring scales (Developed from work by Hollen et al. (2003), Regnard and Hockley (1995) and Oncology Nursing Society (1994)).

Establishing the nursing role

The potential for nurses to be involved in wider aspects of cancer care had been recognised in the Calman Hine report (Calman and Hine, 1995), although little guidance had been

given as to the specific nature of nursing roles. At the time of the study, there were very few lung cancer nurse specialists in the UK, and it was decided that the model of follow-up should be developed in the context of this emerging role. Two nurse specialists were appointed to provide follow-up care, one of whom was funded by Macmillan Cancer Relief. These nurse specialists had already undertaken degrees in cancer nursing and were experienced in the care of patients with lung cancer as well as the outpatient setting. A period of 3 months' training was planned, which enabled the nurses to work closely with other members of the multidisciplinary team, and develop their skills in assessment and symptom management (Table 2). In addition, the need for regular and on-going supervision from medical colleagues and the study co-ordinator was identified so as to provide the nurses with adequate opportunity to talk through issues regarding the patient caseload and aspects of the study process. The nurse specialists were based within an academic department of nursing adjacent to the cancer centre, allowing them access to advice and support in both the academic and clinical settings.

Table 2.

Preparation and on-going training programme for the CNS role.

- Observation of medical clinics and shadowing of Consultants in Respiratory Me
- Working alongside key health professionals involved in lung cancer care includi
- Meeting community palliative care teams in the local area to discuss collaborati

- Linking with other nurses involved in nurse-led initiatives, both locally and nation
 - Meeting with a representative from the Royal College of Nursing to discuss prof
 - Regular meetings with members of the study team to reflect on the developmer
 - Weekly supervision with the study co-ordinator to reflect on positive and difficult
 - Regular clinical supervision with two medical consultants to discuss medical asj
-

Data collection and analysis

During the randomised controlled trial comparing conventional medical follow-up and nurse led follow-up, data on patient survival, quality of life, and patient and general practitioner satisfaction was collected. Methods and findings have been reported elsewhere (Moore et al., 2002). As the trial progressed, it became clear that additional data was needed to inform our understanding of the emerging nature of nurse led follow-up and the experiences of delivering nurse led care. Additional data was collected from three main sources:

1. Patient case-notes: Detailed case-notes were kept by the nurse specialists during the study period recording all contact with patients and relatives. The case-notes recorded the number and length of all contacts with patients and carers, the reason for contact, and descriptions of the nursing interventions implemented. A random sample of half ($n=51$) of these were analysed at the end of the trial period by one of the study co-ordinators (SM). Numerical data were manually counted and summarised to show frequency and

length of contact. Text was analysed to elicit the key areas of care provided by the nurse specialists.

2. Semi-structured interviews: A tape recorded semi-structured interview with each of the nurse specialists ($n=2$) and each of the study co-ordinators ($n=2$) was conducted by a Nurse Researcher who was not directly involved in the trial (HP). The interviews took place approximately six months after each nurse/study co-ordinator started working on the trial and lasted 90–120 min. An interview schedule was used, which focussed on the interviewees' experiences of the trial process and their descriptions of the development of nurse led follow-up care, including aspects which were considered helpful or challenging.

3. Team meetings: Regular team meetings ($n=8$) were held with the study co-ordinators, nurse specialists and principal investigator throughout the trial period to reflect upon and record the study process to date and explore possible development of the model of nurse-led follow-up. These meetings lasted between 90 and 150 min and were tape-recorded also.

The transcripts from the interviews and team meetings were analysed at the end of the study period to identify themes or issues, following a method described by Cresswell (2003, pp. 190–197). This method involved one of the authors (SM) reading through all the transcripts several times to obtain a general sense of the data. This was followed by a coding process; organising the data into categories, and labelling

the categories using the actual language of the nurses and study team from the transcripts. Excerpts from the data were inserted under each category to show as faithfully as possible how the categories emerged. Transcripts were then re-read to ensure the categories identified were an accurate reflection of the data as a whole. The final step of analysis involved making an overall interpretation or meaning of the data from the individual categories identified. This last step was an iterative process involving four of the authors (SM, MW, HP and JC) reading through the analysis to date to agree upon the main themes or issues.

Findings

Nature of the nursing role

The review of the nurse specialists' case-notes generated a detailed picture of the nature of the nursing role in follow-up care. Most patients, on entering nurse-led follow-up, agreed to be contacted by the nurse specialist once a month for a telephone assessment. However, in practice the average number of contacts per patient was three per month, usually by telephone. Frequency of contact with patients and carers naturally increased when patients were unwell or reached particular crisis points, for example when their disease had progressed and they were in need of more information and support.

Patients remained in nurse-led follow-up for between 1 and 27 months, with an average duration of 10 months.

Individual contact ranged from a brief call to confirm an appointment to a two-hour meeting to assess complex symptoms, organise investigations or arrange in-patient admission. Under the nurse-led model of follow-up care, 84% of patients had contact with a palliative care team. Within the telephone and nurse-led clinics, nurse specialists engaged in a number of different roles and interventions with patients. These can be categorised under the following broad areas of care:

- psychological support for the patient and family,
- social and financial support,
- monitoring of disease, assessment of symptoms and comprehensive record keeping,
- coordination and organisation of care, ordering investigations, arranging appropriate appointments, discussion with multidisciplinary team,
- provision of information, practical advice, symptom management, and self care strategies to patients and carers,
- information and advice to health care professionals within the hospital and community, and
- prompt liaison, referral and communication with hospital and community teams and other support agencies.

Nurses' experience of providing follow-up care

Four main themes emerged from the interview and meeting data describing the nurse specialists' experience of providing follow-up care. These are 'training', 'becoming credible', 'emotional burden' and 'making a difference'.

Training

Although the nurse specialists went through a thorough preparation and training period, it was acknowledged that much of their learning could only occur experientially, through the actual 'doing' of the role. Developing new ways of working and tackling challenges as they arose was an important part of developing confidence and skill in their therapeutic work with patients and carers. Assuming responsibility for the medical and support needs of patients on follow-up proved to be extremely challenging. Inevitably, it took time for the nurses to feel comfortable in their new roles:

I think they're both very good but I think they are struggling, because, I mean, the enormity of the responsibility and the change in role really, and they're very used to working within the medical system whereby the nurse is constantly in interaction with the doctors and constantly suggesting things. (Study Co-ordinator A)

The process was made more difficult because the nurses were also part of a research study and felt they too were being 'researched upon'. The perceived expectation to

succeed was huge:

It felt very big, the responsibility of participating in something which feels so very important...the pressure was tremendous. (Nurse A)

At first the responsibility of managing the follow-up process was quite overwhelming, and there was a sense of isolation and 'loneliness' within the role. The nurses were concerned they might 'miss something important' to the detriment of a patient's well-being and/or overall survival:

If the disease comes back and I sometimes think if I don't catch something in time, if the patient wanted extra treatment and if I miss it. (Nurse B)

However, over time the nurses began to develop a more realistic sense of responsibility, acknowledging that, although they were now managing care for this group of patients, they were still very much part of a wider team:

What we're saying is that we're not advocating nurse-alone care ever. What's on hand here is the team to help you in what you're doing. (Nurse A)

Becoming credible

Initially the nurse specialists experienced a degree of hostility from some colleagues as it took time for the new role and model of working to become accepted. Although the study hospitals employed other site-specific nurse specialists, none had experience of working with a nurse

specialist in lung cancer. Some health professionals were sceptical that nurses were skilled enough to manage follow-up care for patients with lung cancer safely. Others felt the role overlapped too much with the work of medical and palliative care teams. A tremendous amount of energy needed to be invested into getting other health professionals to understand and accept the new roles:

The humorous tolerance of those nurses who are doing this strange thing that can't possibly work. It's all a bit of a laugh as far as the doctors are concerned and I think that's quite uncomfortable...I think its suspicion and maybe fear even. I think it's a fear of being exposed and from the point of view of the doctors, that they're not meeting people's needs.
(Study Co-ordinator A)

Consequently, the nurses initially felt they had to avoid 'upsetting' other health professionals and were cautious of 'treading on other people's toes', particularly where role boundaries were blurred or ill-defined. It took time for the nursing role to be taken seriously and for the nurses to earn the confidence and respect of their colleagues:

I think a lot of people think it's a bit of a joke really. Initially I think they did. But now, I think they know we're pretty serious about it and we're serious about getting the best for our patients. (Nurse B)

Since, in the eyes of many, the role still lacked the status of

that of a doctor, the nurses had to work hard to realise the support and autonomy they needed. For example, it took considerable time to obtain secretarial support, and when it was secured, some secretaries would attach low priority to the nurses' letters. Similarly, gaining access to clinic rooms was also a problem:

Getting clinic space was a really, really big issue and actually the nurses (clinic nurses) have been just as resistant about that as the doctors have and the managers have. We are constantly getting thrown out of rooms because the doctors need to see patients and that's fairly frustrating. (Study Co-ordinator A)

Some health professionals voiced concerns to the study team that lung cancer was an inappropriate disease on which to base a nurse led follow-up role because patients were rarely well enough to do without medical intervention. In fact, the very reason for developing the model of care was to tackle the complex nature of problems experienced by patients with lung cancer, many of which were not being addressed under the traditional system of follow-up.

Fears were also expressed that the nurse led model of care would create dependency in patients, an over-reliance on one person and an unrealistic expectation of what health care could provide. Some doctors expressed a concern that the nurses would 'open the flood-gates' to patients' problems. Interestingly, a trend did emerge whereby patients

who were deemed to be well and of good performance status frequently reported more symptoms, psychological problems and functional difficulties when they were assessed by a nurse:

I think they've both (the nurses) have had problems with their baseline assessment because the doctor's dictation has often been—'saw this patient in clinic. He's doing really well. No problems'. That sort of thing—and then the nurses will write a letter saying—'reviewed this patient for the first time. He's severely breathless. He's very worried about money. He can't walk because of arthritis in his hip'—and it's just farcical. You could be writing about two different people. (Study Co-ordinator A)

Emotional burden

The concepts of 'patient-centred care' and 'therapeutic working' with patients and carers were inherent to the nursing model developed within this study:

It's about me being a person and investing myself in them. (Nurse A)

Initially the nurses felt unprepared for this degree of intensity in their relationships with patients and carers. They were also uncomfortable about the sheer breadth of the role:

I didn't anticipate the intensity. I think the work I'm doing now, it's like the work I've done before, but I

think the intensity of the relationship that we build up with patients now is a lot more than I've ever done on a ward ...it's different in that you're available to them for everything. (Nurse B)

Developing long-term relationships with patients and allowing them open access during working hours also added to the emotional burden felt by the nurses.

I felt they were feeling overwhelmed with the emotional burden and the responsibility of the workload. So much so, that it was actually having a real effect on their well-being. (Study Co-ordinator B)

Carrying a pager meant the nurse specialists were on-call during all of their working hours. Patient access was not bounded by clinic times and responsibility for their patient case-load was not bounded by the end of a working day:

There isn't a closure or a cutting off of the relationship like there is in clinic. What I really missed was the benefit of hand-over – the report, because you feel you can off-load what happens in the day. You off-load, you go home. Sometimes you bring your work home with you and you think about it during the night and you can't sleep because you think of what happened. (Nurse B)

From the interviews with the nurse specialists, which at times were quite emotional, it was clear that past painful

events in their own lives could be triggered by the distress they repeatedly came face to face with in their work with this group of patients and their families. Throughout the study, the emotional burden of working closely with a population of patients whose prognosis is poor and who often experience difficult and distressing symptoms that are hard to ameliorate was repeatedly acknowledged. The reality was all too real—that most patients with lung cancer do not get better:

It was close to a bereavement of my own so that didn't make it very easy and I'd grown terribly fond of him and I didn't want somebody that I was fond of dying like that. That has a cost. (Nurse A)

At the start of the study, access to weekly supervision with the study co-ordinator and, separately, with a medical consultant was established. However, it soon became apparent that external clinical supervision would be a useful additional support strategy. This allowed the nurses to talk through some of the more difficult emotional issues that arose without affecting relationships with the study team and immediate clinical colleagues. It also allowed the nurse specialists the opportunity to talk more freely about issues relating to being part of the research study. The nurses acknowledged that it was this range of supportive strategies that enabled them to sustain this intense level of working over time:

I was beginning to develop a much better self-

awareness about what the issues were for me because I'd been in clinical supervision...It really has helped me to work out why I found it hard... developing a better awareness about that really, about why am I doing it, why do I want to do it, why am I staying in something that is so hard. What's going to make it easier, how to ask for help and how not to go under with it. (Nurse A)

Making a difference

Despite the professional and personal challenges of the role, the nurses perceived the new model of follow-up was associated with huge benefits for patients. The nurse-led model attempted to create a supportive environment in which care was more effectively planned and managed, according to the needs of the individual. The nurses came to describe the role as:

organising the journey as the patient wants it (Nurse A), and

tailoring care to individual need. (Nurse B)

Although the role was acknowledged as emotionally demanding, it was also immensely satisfying, as the nurses began to feel their actions were therapeutic in their own right:

It's a lot about giving actually, giving to people a part of yourself maybe and I think really you're happy

doing it because I think we're improving... I think definitely we are making a difference to them coping with what's going on and the families. (Nurse B)

The biggest thing is they've (the patients) an emotional need to feel cared for and hopefully that's what we're doing. Being there and giving them an overwhelming sense of support and to be able to deal with their problems whatever they throw at us. (Nurse A)

This model of working also allowed carers an important, and perhaps more prominent, role in the care of the patient:

She comes with her husband. You'll do an assessment and then we get this little voice come in saying 'you haven't told... (name of nurse) about so and so'. He's very quiet and you can imagine if he was in a medical clinic I don't know that he'd say anything because like he's got to know us, he'll actually contribute sometimes, quite some significant things about how she's feeling or what's happened, what he's worried about. (Nurse A).

Discussion

Over the last ten years, the role of the Lung Cancer Nurse Specialist (LCNS) has emerged and developed widely throughout the UK. The role includes providing continuing support, facilitating communication between hospital and community teams, and helping patients to access advice

and support (NICE, 2005; London and South East Lung Cancer Forum for Nurses, 2004). LCNSs may practise within an area of oncology, respiratory medicine, thoracic surgery or combinations of the three specialities. Recent guidance suggests that each cancer centre/unit should have at least one LCNS (Department of Health, 2004; NICE, 2005; Scottish Intercollegiate Guidelines Network (SIGN), 2005). Based on membership of the National Lung Cancer Forum for Nurses, there are about 250–300 LCNSs currently in the UK (National Lung Cancer Forum for Nurses, personal communication) and work is on-going to identify the scope and nature of their role (Brown and McPhelim, 2006).

The nurse specialist role described in this paper differs from the more typical Lung Cancer Nurse Specialist role that has developed in the United Kingdom in that it focuses solely on supporting patients during follow-up, after completion of initial treatment (if any). More typically, the LCNS role has tended to be all encompassing; working with patients at all stages of the cancer journey. In practice, because of large caseloads and numerous demands on their time, this has resulted in some LCNSs feeling they are forced to ‘spread themselves thinly’ thereby running the risk of diluting their therapeutic effect (Richardson et al., 2002). Often, LCNSs are attached to medical clinics and a large proportion of their time is driven by the needs and consequences of the medical system, for example, supporting patients after a diagnosis of cancer has been given. Because the way in which diagnosis is handled is so critical, there has been a

huge investment of resources into this aspect of cancer care. However, this may leave little time to develop ongoing therapeutic relationships with patients and carers throughout the rest of the care pathway, and the opportunity for involvement in follow-up care, once treatment is completed, may be particularly small.

There is no doubt that diagnosis is an important area in the care of patients with cancer. However, evidence suggests that follow-up is also a significant time in the cancer journey. Patients describe feeling well-supported within the 'treatment-schedule' (Schou and Hewison, 1999) but are known to experience difficulties in emotional and social functioning on coming to the end of treatment (MacBride and Whyte, 1998; Maher, 1982; Wells, 1998). This is poignantly described in patients' self-reports also (Armstrong, 2001; Dennison, 1996). Health care teams are urged to ensure that patients with cancer and their families receive adequate care and support throughout all stages of the cancer trajectory (National Institute for Clinical Excellence (NICE), 2004), and that patients with lung cancer are offered access to nurse specialist led follow-up care (NICE, 2005, SIGN, 2005). The challenge for clinicians is to determine how already-stretched services can be reconfigured and evaluated to ensure needs are addressed and met fully throughout all stages in patients' care.

This paper provides insights into the developmental process of nurses taking on new roles and innovative ways of

working. The experiences of the nurses on this study mirrors the model described by Benner (1984) of the transition from 'novice' to 'expert' nurse. As in Benner's work, the nurses on this study experienced a lack of confidence and unease in their new roles at the beginning of the study, but became more confident as time went by, and as their experience increased. Similar to Benner's (1984) findings, the nurse specialists initially felt they needed a set of rules to guide their decision-making and worried that without guidelines, they were at risk of making errors. However, because the model of follow-up challenged the nature and culture of existing models of care, there were no guidelines to work from. This created a sense of nervousness in the nurse specialists which was compounded when they encountered scepticism of the role in other health care professionals.

The concept of therapeutic nursing was fairly new to the nurses at the beginning of the study. They had to adjust to a way of working which was truly patient-centred and which required them to be available to the patient, allowing disclosure of difficult feelings and attempting to help find meaning in the person's suffering (Lanceley, 1995). Patient-centred care recognises the uniqueness of the individual; paying attention to detail, uncovering meaning in everyday situations, being attentive, available, reliable and true to promises, and understanding the importance of each person's biography and how he or she is seeking to gain an understanding of what is happening (Kitson, 1999).

The experience of the nurse specialists was similar to that described by Bailey (1995) in relation to working therapeutically with patients attending a breathlessness clinic. Bailey (1995) utilises Bion's (1962) work which describes how the mother contains and processes an infant's unmanageable distress, then with time, enables the infant to take it on in a more tolerable form. The nurse specialists providing follow-up defined their role also as 'holding' or 'containing' patients' emotions at times of intolerable stress. However, though rewarding, this intense caring role is acknowledged to place a high demand on nurses (Krishnasamy and Plant, 1998; Moore and National Lung Cancer Forum for Nurses, 2002). This personal cost may be one of the reasons why social and emotional concerns are not always fully addressed with patients with cancer. Health care professionals working with similar groups of patients may, at times, consciously, or subconsciously, protect their own emotional well-being by using blocking techniques to prevent patients from raising emotional concerns. As other authors (Menzies Lyth, 1988; Smith, 1992; Lanceley, 1997) have indicated, working at an emotional level can have consequences for the nurse's self-identity and, unless the work environment facilitates support, the nurse's defences against this anxiety may cause him/her to withdraw. The findings from this study confirm this emotional cost of caring and suggest the provision of adequate support and supervision is essential to enable nurses to sustain this level of working over time. If similar models are to be adopted in the UK, it is imperative to

ensure that time is sanctioned, not only for patient-work, but for reflection and supervision also.

There is a continuing drive to further expand the role of nurses in the UK (Department of Health, 2000) and recent developments have led to a range of advanced practice roles and wider responsibilities for cancer nurses (Ferguson and Kearney, 2000; National Health Service Executive, 2000). A number of studies have identified that nurse specialist-led services can be effective in several areas of cancer care including psychological support (Maughan and Clarke, 2001), symptom management (Bredin et al., 1999), community care (White et al., 1996), and follow-up care (Sardell et al., 2000; Faithfull et al., 2001; Koinberg et al., 2004). However there is concern about the number of different nursing titles that imply an advanced level of knowledge and competence, and the lack of adequate assessment and registration of the education and training in place for such roles (Nursing and Midwifery Council, 2004). The Nursing Midwifery Council (2004) in the UK has identified a need to further define advanced nursing practice and to set standards of proficiency to take account of national developments.

National cancer plans (Department of Health, 2000; Scottish Executive, 2001), frameworks for nursing patients with cancer (Royal College of Nursing, 2003; Scottish Executive, 2004), and guidance from the Royal College of Radiologists (2002) and National Institute for Clinical Excellence, 2004

and National Institute for Clinical Excellence, 2005 confirm that nurses will continue to play a major role in reconfiguring care to better meet the needs of patients with cancer in a complex and ever changing environment. It is vital that we build on this work by recognising the value of qualitative and quantitative evidence to support future progress, developing improved protocols and ensuring that we continue to evaluate the long term implementation of new models of care after clinical trials have been completed (MRC 2000).

Limitations

Findings presented in this paper are based on additional data collection which was embedded within a large randomised trial, rather than from a separate study conceived with its own conceptual and methodological framework. These findings concentrate on the experience of the nurse specialists delivering the model of nurse led follow-up care. The views of general practitioners and patients were elicited through satisfaction questionnaires and are reported elsewhere (Moore et al., 2002; Corner et al., 2000).

The study is limited by the small sample size of nurse specialists involved and the fact that the study took place in a small number of hospital settings only (a cancer centre and three neighbouring unit or district general hospitals). Replication by a larger number of nurse specialists working in other settings would determine the generalisability of the findings. However replication of the study would prove

difficult. At the time the study commenced, there were very few Lung Cancer Nurse Specialists in post and we were able to randomise patients to either medical follow-up alone, or follow-up led by nurse specialists. Now, the care environment has changed and many patients with lung cancer have at least some access to, and contact with, a nurse specialist. Therefore, randomisation to medical care alone, without nurse specialist involvement, would be difficult, if not impossible.

The findings should be considered in light of the fact that the nurse specialists were working within the context of a research study and their experience may differ significantly from the reality of everyday practice. Within the research setting, motivation, support and protected time may be greater and nurses attempting to replicate similar ways of working may experience unforeseen challenges when attempting to incorporate the findings into their own clinical practice (Johnson and Moore, 2003). Adaptation of the model of follow-up care is encouraged and differences should be expected to ensure the needs of individual practice settings are met.

Conclusion

The recommendation that people with lung cancer should be offered follow-up care by nurse specialists (NICE, 2004, 2005) is welcome since this can lead to greater levels of patient satisfaction (Moore et al., 2002). The findings detailed in this paper illustrate that developing nurse led

follow-up for this patient group is challenging and there are many practical and emotional hurdles to be overcome for nurses who take on advanced practice roles. We hope the honest insights presented in this paper will help other nurse specialists in adapting this model of working to suit their own clinical environments. Comprehensive preparation, and continuing support and supervision are essential to ensure sustainability of such roles.

References

Armstrong, 2001 L. Armstrong, *It's not about the bike. My journey back to life*, Vintage Yellow Jersey Press, London (2001).

Bailey, 1995 C. Bailey, Nursing as therapy in the management of breathlessness in lung cancer, *European Journal of Cancer Care* **4** (1995), pp. 184–190. [View Record in Scopus](#) | [Cited By in Scopus](#)

Benner, 1984 P. Benner, *From novice to expert. Excellence and power in clinical nursing practice*, Addison-Wesley, Menlo Park, California (1984).

Bion, 1962 W. Bion, *Learning from experience*, *Seven Servants*, Jason Aronson, New York (1962).

Brada, 1995 M. Brada, Is there a need to follow-up cancer patients?, *European Journal of Cancer* **31A** (1995) (5), pp. 655–657. [SummaryPlus](#) | [Full Text + Links](#) | [PDF \(412 K\)](#) | [View Record in Scopus](#) | [Cited By in Scopus](#)

Bredin et al., 1999 M. Bredin, J.L. Corner, M. Krishnasamy, H. Plant, C. Bailey and R. A'Hern, Multicentre randomised controlled trial of nursing intervention for breathlessness in patients with lung cancer, *British Medical Journal* **318** (1999), pp. 901–904. [View Record in Scopus](#) | [Cited By in Scopus](#)

Brown and McPhelim, 2006 Brown, L., McPhelim, J., 2006. UK Lung Cancer Nurse Audit. One is not enough! British Thoracic Oncology Group Poster Abstract No. 14.

Calman and Hine, 1995 K. Calman and D. Hine, A policy framework for commissioning cancer services. A report by the expert advisory group on cancer to the chief medical officers of England and Wales, Department of Health, London (1995).

Collins et al., 2004 R.F. Collins, H.L. Bekker and D.J. Dodwell, Follow-up care of patients treated for breast cancer: a structured review, *Cancer Treatment Reviews* **30** (2004) (1), pp. 19–35. [SummaryPlus](#) | [Full Text + Links](#) | [PDF \(417 K\)](#) | [View Record in Scopus](#) | [Cited By in Scopus](#)

Corner et al. Corner, J., Moore, S., Haviland, J., Wells, M., Salmon, E., Normand, C., Brada, M., O'Brien, M., Smith, I., 2000. Development and evaluation of an alternative model of nurse led follow-up in the management of patients with lung cancer. Final report. NHS National Cancer Research and Development Programme.

Cresswell, 2003 J.W. Cresswell, *Research Design:*

Qualitative, quantitative, and mixed method approaches (second ed), Sage Publications Inc, California (2003).

Dennison, 1996 A. Dennison, *Uncertain Journey: A Woman's Experience of Living with Cancer*, The Patten Press, Cornwall (1996).

Department of Health, 2004 Department of Health, *Manual for Cancer Services*, DOH, London (2004).

Department of Health, 2000 Department of Health, *The NHS Cancer Plan. A plan for investment, A plan for reform*. DOH, London (2000).

Faithfull et al., 2001 S. Faithfull, J. Corner, J. Meyer, R. Huddart and D. Dearnley, Evaluation of nurse-led follow-up for patients undergoing pelvic radiotherapy, *British Journal of Cancer* **14** (2001), pp. 1853–1864. **Full Text** via CrossRef | View Record in Scopus | Cited By in Scopus

Ferguson and Kearney, 2000 A. Ferguson and N. Kearney, Towards a European framework for cancer nursing. In: N. Kearney, A. Richardson and P. Di Giulio, Editors, *Cancer Nursing Practice A Textbook for the Specialist Nurse*, Churchill Livingstone, Edinburgh (2000).

GIVIO Investigators, 1996 GIVIO Investigators, Impact of follow-up testing on survival and health related quality of life in breast cancer patients, *Journal of the American Medical Association* **271** (1996), pp. 1587–1592.

Grunfeld et al., 1993 E. Grunfeld, D. Mant, P. Yudkin, R.

Adewuyi-Dalto, D. Cole, J. Stewart, R. Fitzpatrick and M. Vessey, Routine follow up of breast cancer in primary care: randomised trial, *British Medical Journal* **313** (1993), pp. 665–669.

Hollen et al., 2003 P.J. Hollen, R.J. Gralla, M.G. Kris and L.M. Potanovich, Quality of life assessment in individuals with lung cancer: Testing the Lung Cancer Symptom Scale (LCSS), *European Journal of Cancer* **29A** (2003) (suppl 1), pp. S51–S58.

Johnson and Moore, 2003 M. Johnson and S. Moore, Research into practice: the reality of implementing a non-pharmacological breathlessness intervention into clinical practice, *European Journal of Oncology Nursing* **7** (2003) (1), pp. 33–38. [Abstract](#) | [Abstract + References](#) | [PDF \(111 K\)](#) | [View Record in Scopus](#) | [Cited By in Scopus](#)

Kievit and Bruivels, 1995 J. Kievit and D.J. Bruivels, Detection of recurrence after surgery for colorectal cancer, *European Journal of Cancer* **31A** (1995) (7/8), pp. 1222–1225. [SummaryPlus](#) | [Full Text + Links](#) | [PDF \(479 K\)](#) | [View Record in Scopus](#) | [Cited By in Scopus](#)

Kitson, 1999 A. Kitson, The essence of nursing, *Nursing Standard* **13** (1999) (23), pp. 43–46.

Krishnasamy and Plant, 1998 M. Krishnasamy and H. Plant, Developing nursing research with people, *International Journal of Nursing Studies* **35** (1998), pp. 79–84. [SummaryPlus](#) | [Full Text + Links](#) | [PDF \(657 K\)](#) | [View](#)

Record in Scopus | Cited By in Scopus

Koinberg et al., 2004 I.L. Koinberg, B. Bridlund, G.B. Engholm and L. Holmberg, Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomised study, *European Journal of Oncology Nursing* **8** (2004), pp. 109–117. SummaryPlus | **Full Text + Links** | PDF (203 K) | View Record in Scopus | Cited By in Scopus

Krishnasamy and Wilkie, 1999 Krishnasamy, M., Wilkie, E., 1999. Lung cancer: patients', families and professionals' perceptions of health care need. A national needs assessment study. London: Macmillan Practice Development Unit/Centre for Cancer and Palliative Care Studies.

Lanceley, 1995 A. Lanceley, Emotional disclosure between cancer patients and nurses. In: A. Richardson and J. Wilson-Barnett, Editors, *Nursing research in cancer care*, Scutari Press, London (1995).

Lanceley, 1997 Lanceley, A., 1997. The voice of feeling: nurses responses to cancer patients emotional experience. 14th Annual Conference of the British Psychosocial Oncology Society, London.

London and South East Lung Cancer Forum for Nurses, 2004 London and South East Lung Cancer Forum for Nurses, Guidelines on the role of the specialist nurse in supporting patients with lung cancer, *European Journal of Cancer Care* **13** (2004), pp. 344–348.

MacBride and Whyte, 1998 S.K. MacBride and M.N. Whyte, Survivorship and the cancer follow-up clinic, *European Journal of Cancer Care* **7** (1998), pp. 47–55. **Full Text** via CrossRef | View Record in Scopus | Cited By in Scopus

Maher, 1982 E.L. Maher, Anomic aspects of recovery from cancer, *Social Science and Medicine* **16** (1982), pp. 907–912. Abstract | **Abstract + References** | PDF (774 K) | View Record in Scopus | Cited By in Scopus

Maughan and Clarke, 2001 K. Maughan and C. Clarke, The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality, *Journal of Clinical Nursing* **10** (2001), pp. 221–229. **Full Text** via CrossRef | View Record in Scopus | Cited By in Scopus

Medical Research Council, 2000 Medical Research Council, 2000. A framework for the development and evaluation of RCTs for complex interventions to improve health, MRC, London.

Menzies Lyth, 1988 I. Menzies Lyth, The functioning of social systems in a defence against anxiety. In: I. Menzies Lyth, Editor, *Containing anxiety in institutions*, Free Association Books, London (1988).

Moore et al., 1999 S. Moore, J. Corner and F. Fuller, Development of nurse-led follow-up in the management of patients with lung cancer, *NTresearch* **3** (1999) (6), pp. 432–445. **Full Text** via CrossRef

Moore et al., 2002 S. Moore, J. Corner, J. Haviland, M. Wells, E. Salmon, C. Normand, M. Brada, M. O'Brien and I. Smith, Nurse led follow-up and conventional medical follow-up in the management of patients with lung cancer: randomised trial, *British Medical Journal* **325** (2002), pp. 1145–1147. [View Record in Scopus](#) | [Cited By in Scopus](#)

Moore and National Lung Cancer Forum for Nurses, 2002 S. Moore and National Lung Cancer Forum for Nurses, A survey of nurse specialists working with patients with lung cancer, *European Journal of Oncology Nursing* **6** (2002) (3), pp. 169–175. [Abstract](#) | [Abstract + References](#) | [PDF \(143 K\)](#) | [View Record in Scopus](#) | [Cited By in Scopus](#)

National Health Service Executive, 1998 National Health Service Executive, 1998. Guidance on commissioning cancer services: Improving outcomes in lung cancer, NHS Executive, London.

National Health Service Executive, 2000 National Health Service Executive, 2000. The nursing contribution to cancer care. A strategic programme of action in support of the national cancer programme. NHS Executive, London.

National Institute for Clinical Excellence, 2004 National Institute for Clinical Excellence, 2004. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. NICE, London.

National Institute for Clinical Excellence, 2005 National Institute for Clinical Excellence, 2005. Lung Cancer. The

diagnosis and treatment of lung cancer. Clinical Guideline 24. NICE, London.

Nursing Midwifery Council, 2004 Nursing & Midwifery Council, 2004. Consultation of a framework for the standard for post-registration nursing. NMC, London.

Oncology Nursing Society, 1994 Oncology Nursing Society, 1994. Radiation therapy patient care record. ONS, Philadelphia, USA.

Radford et al., 1997 J.A. Radford, A. Eardley, C. Woodman and D. Crowther, Follow up policy after treatment for Hodgkin's disease: too many clinic visits and routine tests. A review of hospital records, *British Medical Journal* **314** (1997), pp. 343–346. View Record in Scopus | Cited By in Scopus

Regnard and Hockley, 1995 C. Regnard and J. Hockley, Flow Diagrams in Advanced Cancer and Other Diseases, Edward Arnold, London (1995).

Richardson et al., 2002 A. Richardson, D. Halliday and J. Wilson-Barnett, Evaluating the Impact of Introducing Lung and Colorectal Nurse Specialists into the South East London Cancer Network, King's College University of London, London (2002).

Royal College of Nursing, 2003 Royal College of Nursing, A Framework for Adult Cancer Nursing, RCN, London (2003).

Royal College of Radiologists, 2002 Royal College of

Radiologists, Breaking the Mould: Roles Responsibilities and Skill Mix in Departments of Clinical Oncology, RCR, London (2002).

Sardell et al., 2000 S. Sardell, G. Sharpe, S. Ashley, D. Guerrero and M. Brada, Evaluation of a nurse-led telephone clinic in the follow-up of patients with malignant glioma, *Clinical Oncology* **12** (2000), pp. 36–41. [Abstract](#) | **Abstract + References** | [PDF \(92 K\)](#) | **Full Text** via CrossRef | [View Record in Scopus](#) | [Cited By in Scopus](#)

Schou and Hewison, 1999 K.C. Schou and J. Hewison, Experiencing Cancer: Quality of Life in Treatment, Open University Press, Buckinghamshire (1999).

Scottish Executive, 2004 Scottish Executive, 2004. Nursing people with cancer in Scotland: A framework. SE, Edinburgh.

Scottish Executive, 2001 Scottish Executive, 2001. Cancer in Scotland: Action for change. SE, Edinburgh.

Scottish Intercollegiate Guidelines Network, 2005 Scottish Intercollegiate Guidelines Network, 2005. Management of patients with lung cancer. A national clinical guideline. SIGN, Edinburgh.

Smith, 1992 P. Smith, The emotional labour of nursing, How nurses care, Macmillan Education Unit, London (1992).


Smith, 2003 T.J. Smith, Evidence based follow-up of lung cancer patients, *Seminars in Oncology* **30** (2003) (3), pp.

361–368. [View Record in Scopus](#) | [Cited By in Scopus](#)

Standing Medical Advisory Committee, 1994 Standing Medical Advisory Committee, 1994. Management of lung cancer: current clinical practices. Report of a Working Party chaired by Professor J.M.A.Whitehouse.

Wells, 1998 M. Wells, The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment, *Journal of Advanced Nursing* **28** (1998) (4), pp. 840–848. [View Record in Scopus](#) | [Cited By in Scopus](#)

White et al., 1996 N.J. White, B.A. Given and D.N. Devoss, The advanced practice nurse: meeting the information needs of the rural cancer patient, *Journal of Cancer Education* **11** (1996), pp. 203–209. [View Record in Scopus](#) | [Cited By in Scopus](#)

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