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The changing face of cancer care in the United Kingdom: can nurses help to structure new services?

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ABSTRACT

Objective: The concept of the lead cancer nurse is relatively new; no models of practice are available. An evaluation of lead cancer nurses was undertaken to identify core elements of success associated with this role.

Design: A two-stage multiple case study was used. In Stage One, information was collected about post holders, working contexts, strategic aims and evidence of achievements from lead nurses, lead clinicians and senior nurses. Stage Two explored the processes that enhanced and inhibited development of the lead nurse role.

Setting and sample: Site-visits were made to 12 Macmillan Lead Cancer Nurses throughout the U.K.

Data collection and analysis: Detailed information from interviews, observations and documentary materials were analysed using a framework that emphasised four key areas: assessment of current service, promotion of evidence-based practice, contribution to strategic decision making and consumer perspectives.

Results: Enhancing factors important to the lead cancer nurses were the ability to: utilise decision making power, build alliances and accommodate to a changing environment. Factors found to hinder achievement were: major changes in service and

policy, restricted resources and the cancer site-specific structure of health service provisions.

Conclusions: Further and greater contributions to cancer care from lead nurses require influential partnerships within local health care organisations and wider networks.

Key words: lead cancer nurse, lead nurse, cancer services, leadership

INTRODUCTION

Compared with some of its neighbouring countries in Europe, the U.K. is attributed with lower preventative and treatment success rates of cancer (Boyle et al 2003). The priority to improve health care for people affected by cancer is high on the agenda for reform of the National Health Service (NHS) in the U.K. and is reflected in major government strategy publications such as the NHS Plan (Department of Health 2000a) and the NHS Cancer Plan (Department of Health 2000b). Influential documents such as the Calman-Hine Report (Calman & Hine, Department of Health and Welsh Office 1995) have been at the forefront in prioritising the areas of increased involvement of patients and care based on evidence of best practice supported by central government guidance. Nurses, by virtue of their extensive input into the care of cancer patients both in hospital and the community, are considered central to the movement to improve and streamline cancer services in the U.K. (Nursing Contribution to Cancer Care, Department of Health 2000c). In the context of addressing the National Guidance on Commissioning Cancer Services (Department of Health 1996, 1997, 1998) the contributions of nurses are essential to the areas of communication, implementation of policy, psychosocial support, membership of multidisciplinary teams and partnership (in decision making) with patients (Booth et al 2001).

The Calman-Hine Report (1995) was written by an expert advisory group on cancer for the purpose of informing the chief medical officers of England and Wales about ways to improve health care for cancer patients. The recommendation was made to

develop cancer services based on their delivery from three defined locations: primary care in the local community, cancer units at general hospitals and cancer centres with specific expertise. As a result of the influential Calman-Hine Report, consultant grade clinician posts were created in order to facilitate, organise and coordinate high quality, comprehensive cancer services throughout the country. In most organisations, the title of Lead Clinician was bestowed upon senior medical or surgical consultants who agreed to take on the new role in tandem with continuing clinical responsibilities. In addition, although not explicitly called for in Calman-Hine, lead cancer nurse posts also began to emerge. This led to a situation where lead post holders (both medical and nursing) had the potential to communicate across disciplines, work closely with each other and with members of the professions allied to medicine. In order to ensure appropriate priority was given to cancer and palliative services, considerable networking between community and acute health care services was envisaged. The idea was that lead cancer nurses would work at senior levels within centralised organisations such as acute hospitals. They would complement the work of lead cancer clinicians and facilitate the necessary strategy and planning to ensure that the nursing aspects of the transformed cancer and palliative care services were identified and nurtured.

Macmillan Cancer Relief in 1998 was at the forefront of this development in cancer nursing and had entered into funding arrangements to support a number of lead cancer nurse posts in England, Scotland and Wales. The concept of the lead cancer nurse was then new and therefore no models of effective practice were available to those setting

up posts. The situation was one of diversity in lead cancer nurse posts, with remits being as varied as working arrangements. Macmillan Cancer Relief recognised the opportunity to commission a structured evaluation of lead cancer nurse posts. This study was undertaken by nurse researchers at the University of Manchester. An expert advisory panel was set up to help guide the work.

STUDY AIM

The aim of the study was to monitor the introduction of Macmillan Lead Nurses and to characterize core elements of these posts.

DESIGN

Participating sites had lead nurse posts, which had been developed in response to local circumstances, so we anticipated variety in role and scope. It was therefore important to identify areas of activity considered important in a wide variety of settings. A series of meetings and a focus group discussion attended by all managers within Macmillan who had commenced (or were considering) funding lead cancer nurse posts resulted in the identification of four key areas of potential lead cancer nursing activity. There was consensus that these were congruent both with emerging cancer and palliative care policy within the NHS and with the priorities of Macmillan Cancer Relief. These were subsequently utilised to focus both data collection and analysis. The four key areas were:

- The assessment/audit of current service
- The promotion of evidence based practice
- Making a contribution to the making of strategic decisions
- Consumer perspectives

SAMPLE

All twelve sites where a Macmillan Lead Cancer Nurse was in post before the end of September 1999 were included. Key informants from these sites, which included England, Scotland and Wales, contributed to the first stage of the study. Following this, two of the original sites were studied in depth. These latter were selected to reflect variation in terms of geographical size, previous experience of the lead nurse and organisational structures.

METHOD

The study was designed as a two-stage case study (after Yin 1994). The method is considered appropriate for appreciating the complexity of organisational phenomena, and is suitable for use with contemporary events, where relevant behaviours cannot be manipulated and where a variety of types of evidence is anticipated.

Stage One (exploratory) focused on collecting information about post holders, the

post, working contexts, perceptions about strategic aims and evidence of achievements from lead nurses, lead clinicians and senior nursing colleagues.

Stage Two (explanatory) examined the processes that enhance and inhibit the effective development of lead nurse posts.

In order to gain maximum understanding from each site, data were collected using three sources, namely: documentary material, observations and interviews. The emphasis on the four key areas of nursing activity originally identified during the consultation was maintained throughout. Examples of successful achievements from both stages were evaluated to determine the range of lead nurse activity. This exercise then assisted us to pinpoint key enabling and hindering factors associated with the four key areas.

A wide range of documentary material was gathered from each of the study sites (Box 1). These included formal documents such as job descriptions, hierarchical diagrams of key personnel within the health care organisation, strategy papers, action plans and progress reports and patient focused materials such as core care plans, patient information and bids for service development projects. In addition, there was a textual examination (see Booth et al 2001) of the then available guidance documents (commissioning of breast, colorectal and lung cancer services). This helped to identify areas where national policy suggested the emerging role of a lead cancer nurse could impact on service development.

Box 1: Sources of documentary material obtained from study sites

Original and updated job descriptions

Organisational diagrams

Strategy papers concerning cancer nursing and cancer nursing education

Six monthly reports to Macmillan Cancer Relief

Minutes of meetings chaired by the lead nurse

Action plans

Bids for developmental projects and specialist nursing staff

Patient information

Core care plans

Observations were of meetings and conversations. These together with notes concerning working environments were brought together as field notes and summaries. Twenty-six key informants were included in the study and interviews were tape-recorded whenever practicable (Table 1).

Table 1: Number of informants interviewed and audio taped

Position of informant	Number interviewed	Number audio taped
Lead cancer nurse	12	12
Lead cancer clinician	8	7
Senior nurse	2	-
Cancer services manager	2	-
Consultant palliative medicine	1	-
Lead general practitioner	1	1
Total number informants	26	20

ANALYSIS

The broad data collection processes yielded an abundance of information, which was managed throughout the study using a structured and systematic framework for recording, organising, displaying and analysing qualitative materials derived from Miles and Huberman (1994) and Richie and Spencer (1994). This approach produced a series of functional matrices. Data from audiotapes were transcribed and together with observational and documentary data were subjected to a thematic content analysis, drawing on data, which supported or refuted assumptions embedded in the four core areas. Data from both stages of the study are presented together.

RESULTS

Characteristics of the Lead Nurses

- Time in post at the point of interview ranged from one week to 16 months.
- Most of the lead nurses had a separate oncology certificate and oncology experience (usually as a ward manager or clinical nurse specialist) and six had a Masters degree in a related area (e.g. cancer nursing, health studies, health management).
- Typically, they had a first degree, were on senior grade nursing salaries and had worked in specialist cancer settings.
- Only two lead nurses reported that they had previous experience holding a post with some strategic planning duties (e.g. planning services, putting policy into practice or responding to local needs).

Achievements

1 Audit/assessment of current cancer services

At all sites we identified this activity. Assessing the current situation was widely considered by lead cancer nurses and their colleagues to be an essential baseline for planning the future of cancer services.

One of the first actions I took in this post was to do a thorough analysis of the state of cancer services...I needed to identify who

and what were out there.

Sites were found to have utilised a range of assessment methodologies such as the use of census and benchmarking questionnaires; tabling, mapping and auditing; S.W.O.T (strengths, weaknesses, opportunities and threats), P.E.S.T. (political, economic, social and technical) and needs-gap analyses.

In response to the above assessments, there were instances where it was evident that lead nurses had contributed directly to the development of services. Examples included:

- The implementation of patient held records, chemotherapy cards, letters to GP (re: cytotoxic toxicity)
- Introduction of nurse led peripherally inserted central catheter (PICC) clinics for the administration of chemotherapy
- The development of patient information
- Working with others to ensure accreditation of oncology unit
- Putting forward numerous successful bids for additional nursing staff (e.g. chemotherapy nurse, head and neck nurse specialist, palliative care hospital support nurse)

We noted from the above that many post holders had indeed acquired sufficient

authority to develop and implement change.

2 Promotion of evidence based practice

Lead nurses were finding a wide range of creative and practical opportunities to further the use of evidence throughout their sphere of influence and frequently implemented a multidisciplinary perspective. At some sites nurses coordinated the production, distribution and review of cancer information aimed at both staff and patient populations.

I get a load of interesting articles on cancer care and say to people, oh, I have read an article on for example, the relationship between patients and cancer nurses or the importance of a nurse being with the consultant when bad news is broken...and just ask if they are interested in seeing the particular article, or I just give it to them.

I coordinated the production of the Newsletter that is widely distributed throughout the region. The aim of the newsletter is to communicate and share developments of the Cancer Unit and disseminate good practice to the wider community.

There was evidence of the utilisation of protocols and standards, distribution of manuals of core care plans, promotion of newsletters and existing study days. We found lead nurses who themselves established professional forums, organised workshops, study days and courses. In addition some lead nurses were asked to advise on matters requiring clinical expertise at local, regional and national level.

I was asked to establish the Regional Chemotherapy Administration Group to develop a common protocol and share good practice.

I'm getting a view on palliative care services for an elite

assessment that is going on in this country. It's a very big project that we are all [Lead Cancer Team] involved in.

There were cases where they were key to new local developments to help spread best practice (e.g. oncology link nurses, research and audit groups and computerised systems for the use of nurses).

We are looking at the concept of link nurses, we are piloting that idea...they can act as a resource. Nurses, particularly in the community, would then know who to contact for any special help or for the appropriate person to contact to help a patient.

3 Contribution to strategic decision making

There were explicit contributions to planning. During the course of the investigation, all twelve lead nurses had written or revised a Cancer Nursing Strategy that would be used as a guide to the development of nursing within cancer care services. In some instances, a Cancer Education Strategy was also prepared, which specified training requirements for nursing and associated professions. Lead nurses spent time and energy meeting with the full range of health professionals at all levels to explain their role and try to gain trust. They were very aware of the importance of gaining membership on working groups, policy boards, steering groups and regional/national networks. Ensuring that their voice was heard in the places where decisions were being made was an important aspect of their endeavours during the period of our study, as reflected in the following response to being asked 'What would you say are your main strategies for achieving your goals?'

I think it would be working on relationships with the directors of nursing services...I arrange to meet them every two months to

make sure that the things that I am working on are really important in terms of their priorities.

I think I am very lucky in the sense that to date the directors of nursing are very supportive...it gets me over many of the major obstacles that I have certainly faced in other positions.

4 Consumer perspectives

In looking for evidence of activity relating to the perspectives of individual patients/families and their local communities, we found some examples. These included surveys, audits, focus groups and face-to-face interviews. The development of patient leaflets at one site was a good case in point.

Whenever we create any sort of leaflet we have involved the patients in its creation, get patients to proof read it. It goes to local support groups for their opinion...then it is reviewed yearly and again, if there are any changes, the users are involved in those changes.

However, this was an area of difficulty. Some respondents found themselves unsure about how to incorporate consumer perspectives into service developments. The process of making arrangements to obtain the views of patients proved to be very difficult for some.

The closest we have come to speaking to patients has been through the needs assessment process. We spoke to 12 patients and it was a huge piece of work. Absolutely enormous job to identify patients who are well enough to speak, whose GP[general practitioner] was willing for them to speak, whose carer was willing for them to speak, who was available on the day...It took 83 GPs to identify 12 patients.

This was an area where lead nurses felt they would benefit from support from either

within or outside their immediate organisation.

The cancer services group was set up between the healthcare professionals and voluntary organisations just to look at what they wanted out of the service...the uptake has been disappointing. I have written to all the organisations again. We really need their support in this.

Factors that assist and hinder the development of the lead nurse

Throughout the study we sought to uncover other aspects of the situation that assisted lead nurses to overcome difficulties and produce successful outcomes. We also uncovered aspects, which were likely to hinder their achievements.

Learning needs

Managing learning whilst in post was an important aspect of the experience. Throughout our study it became apparent that lead nurses were required to learn a great deal in a short space of time if they were to achieve their goals. Despite their differences in qualifications and previous experience, all participants commented to some degree that they felt they lacked relevant skills and experience. In certain instances this could undermine confidence.

I think I have to start working on pathways and the delivery of care and working in that sort of way...but I still don't feel equipped to do that yet...I don't feel prepared for that at all. I feel totally overwhelmed by that project.

Moreover this respondent did not have a clear plan to enable her to meet the learning requirements. We felt that support and mentorship would have helped.

Utilising decision making power and building alliances

All lead nurses recognised the importance of developing advantageous multi-professional relationships with colleagues closely associated with the delivery of cancer services. Post holders who seemed to flourish had ensured their views were heard by senior medical, nursing and management personnel within the organisation.

I work closely with Directors of Nursing and Managers all the way through. Obviously I cannot be there at every point, so it is just identifying the key people and key points.

My main strategy is getting people together to recognise how we can best meet the needs of patients...everything is based around that and I make sure this message is heard loud and clear.

I sit on all the strategy groups, all three hospitals...with the directors of nursing and all the clinicians...so I get a good feel for what they are talking about.

Another lead nurse was able to express the value of building up communication within a broader context.

It is important that the Macmillan Lead Nurse works in partnership with others and develops local, regional and national networks.

This respondent showed how alliances could reach outside the organisation within which the lead nurse was based. Developing these external sources of support had the potential to broaden the post holders' horizons and help them understand their particular service setting in a rapidly changing policy environment.

Lack of resources

We observed that the ability to recognise and harness the help of powerful colleagues in nursing, medicine and management was essential. For instance, lack of resources could be an insuperable barrier without practical support from colleagues within the organisation. A lead nurse expressed her worry and frustration about her efforts to deal with the financial situation and the consequent impact on staffing levels. She expresses a feeling of not being understood.

I just feel that when every avenue is explored, there is a barrier...at the bottom line the barrier is finance...But it is urgent, they just don't understand...If our full-time nurse leaves, gets pregnant or...God forbid, our whole service collapses. That is how dangerous it is.

Sometimes the lack of resource was very basic. In answering a question about what would assist her to achieve her plans, a lead nurse responded

A filing system...that would help. [It noted during this interview that the lead nurse's files and various documents were all piled up on the floor of her office].

Some sites were successful in obtaining external funding for newly devised projects, but this was not universally the case. In addition, the time and effort necessary to achieve external monies should not be underestimated. Time was another resource often in short supply.

It's the mental pressure on yourself that you feel that you should be working 12 hours a day delivering paper after paper on your goals and that your objectives should be achieved within 6 months instead of a year.

Accommodation to a changing environment

Lead cancer nurses had to cope with frequent developments in NHS policy, for example: NHS Cancer Plan (Department of Health 2000a) and The Nursing Contribution to Cancer Care (Department of Health 2000b). Such governmental policy statements can provide an impetus for rapid change, but from the perspective of the lead nurse it means the post holder must be able to function effectively even when the goal posts keep moving. Mergers and restructuring of health service organisations were frequently mentioned as a major hindrance to accomplishing anything. At one site, every senior colleague within the 'old' hospital management organisation, Chief executive, Chief nurse, Directorate manager and even Lead Cancer Clinician, was replaced during the course of the two year investigation.

[from a lead clinician] I think these particular posts ...are right at the cutting edge of change. Now when we are dealing with changed things, there are a lot of unhappy people out there...you may have to deal with chief executives who are going to lose their jobs through mergers and so forth, it's quite hard, I think, sometimes.

Perhaps the most challenging aspect of this type of post was therefore the ability to respond to the inevitable 'moving of goalposts', which all lead nurses experienced throughout the duration of this investigation.

People are under an awful lot of pressure...[during a hospital merger]. So if you want something done, you have to be concise, succinct...I will say 'I need 15 minutes of your time, I need to discuss this' and will usually send a little resume on a piece of paper with pointers, so they know what I am coming for.

Understanding for colleagues was an important facet:

It's helping them to deal with it [major changes in service delivery] and helping them to understand the changed management because I think that is the key issue here; that all human beings run away hurt at times from changes because it is uncomfortable. It's allowing them to understand it's OK to feel like that...

However, in addition to the climate of policy and structural uncertainty which made future planning so problematic, publicity over nurse consultant posts (first mooted during the time of this study) resulted in considerable professional uncertainty:

Will a nurse consultant in cancer care be appointed to replace the lead nurse? Is it wise to let go of clinical skills?

We need to be very clear about identifying the differences between the lead nurse, the consultant nurse and clinical nurse specialist.

The effective post holder therefore was a skilled communicator, able to identify goals and make plans, able to construct helpful alliances, garner practical help and be sensitive to the effects of change on individuals.

Structure of service provision

There was some tension inherent in trying to bring a unifying approach to cancer services when care is organised according to cancer site-specific departments (e.g. breast surgery, haematology). Lead nurses have endeavoured to bring the expertise of cancer nurses to all patients who may benefit (e.g. administration of cytotoxic chemotherapy, management of pain). In an example of this phenomenon relating to a meeting with community services, one lead nurse said:

I was asking them all to tell me what services they had for cancer care. It was interesting, because some of them see cancer services as only palliative care.

Issues were seen to be even more difficult to manage in certain sites. It was noted that these were places where there was a lack of clarity between the role of the lead cancer clinician and the lead cancer nurse or where there were strained relationships within the cancer team. On the other hand, our work (Booth et al 2001) with national guidance on cancer commissioning suggested that properly supported by colleagues with a shared vision, lead cancer nurses were well placed to enhance clinical improvements.

DISCUSSION

The implementation of the NHS Cancer Plan (Department of Health 2000a) will depend upon nursing leaders at local, regional and national levels. The Nursing Contribution to Cancer Care (Department of Health 2000c) outlined a programme of strategic action for leaders in cancer nursing whose contributions are intended to make an impact on service delivery. In the course of this study we have found that within the recommendations made in the Guidance on Commissioning Cancer Services (Department of Health 1996, 1997, 1998) nursing input is essential to many aspects of cancer services and can influence positive health outcomes.

These policies provide rare opportunities for nurses to reveal the values and virtues of cancer nursing and to show that they are making a crucial impact on service delivery. From our work with these pioneering lead cancer nurses in the U.K. it is apparent that

they must be provided with the preparation, resources and guidance necessary to encourage them to go forward. The lead nurse role was very new when this work was carried out. Job descriptions and specifications were very varied and contracts tended to be fixed term. Together these difficulties help to explain why a number of sites had difficulty in finding suitably qualified applicants. This meant that at the start of their appointment few lead nurses in the study actually had any experience working at this level, no role models were available and their organisations had no knowledge of the lead cancer nurse role. Consequently, everybody involved experienced a very steep learning curve. We are aware that the situation may now be more straight forward following the publication of the Manual of Cancer Services Standards (Department of Health 2000d) which has a clear policy concerning lead nurses.

We found that despite their problems, all sites showed the lead cancer nurse had been instrumental in positive change. All achieved substantial progress in the four core areas (assessment of current service, promotion of evidence based practice, contribution to strategic decision making and consumer perspectives), implemented numerous service developments and made plans to address longer term objectives.

Establishing organisational power, making contacts and managing mergers and changes in national policy seem essential. The ability to build, contribute to and lead networks at local, regional and national levels has emerged as an important activity associated with effective action. Also, the development of successful interpersonal relationships with members of the lead cancer team and participants of larger forums,

committees and working parties was identified as being crucial to success.

The experiences of the lead nurses who have participated in this study are congruent with much of the social science literature written on leadership and authority. As developing leaders of cancer nurses, the nurses in the study have already exhibited many of the attributes associated with leadership within a public sector organisation. Interpersonal behaviours such as communicating with, motivating, encouraging and involving people are key activities associated with leaders, in contrast to organisational managers who are most frequently involved in planning, organising, directing and controlling (Mullins 1999). We found the post holders were able to take responsibility and be accountable for implementing cancer nursing strategies and function effectively within a leadership role.

The development of authority within the workplace was noticeably more difficult to achieve and lack of authority was exposed as a particular area of difficulty for the lead nurses. Classically, Weber (1964) explains that in a bureaucratic organisation, such as a NHS acute care hospital, authority is based on the acceptance of formal rules and procedures i.e. 'legal-rational authority'. In this context authority is derived mainly from hierarchical positions within the organisation.

We consider that issues concerning appropriate authority should be explored and made explicit. Many lead nurses did not have a clearly defined place within the hierarchical pyramids of NHS hospitals and community health care organisations and even their closest colleagues were unsure about the nature of their role. Lack of clarity about the

boundaries of the lead nurse/lead clinician responsibility was particularly difficult. This underlines why powerful partnerships were essential and the most influential people within hospitals, primary care organisations and health authorities should be accessible to offer help and contacts. In addition, nursing leaders and academics could introduce lead nurses to useful resources at regional and national levels.

IMPLICATIONS

We consider that many of the messages from this investigation may have currency for the many nurses in leadership roles who will be required to be increasingly active in facilitating the improvement of cancer care. This investigation has confirmed that it is important for nurses in senior and new posts to be facilitated to overcome difficulties not only within the organisation but to help them accommodate to external influences. When faced with hospital mergers, restricted resources and constant changes in national policy, leadership qualities with a strong emphasis on interpersonal behaviours were insufficient to equip lead cancer nurses to become effective players in the effort to improve cancer care.

Overall we have found that success in these lead roles is not simply about ideal characteristics pertaining to the post holder, it is concerned with a working partnership between the nurse and the organisation.

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