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ORAL

A survey of nurse specialists working with patients with lung cancer

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In the last five years there has been a huge increase in the number of Lung Cancer Nurse Specialists in the United Kingdom. This has been due partly to the overall expansion of nurse specialist posts but also, more specifically, in response to the recognised need to improve existing services for patients with lung cancer. Recent research has suggested that the involvement of specialist nurses in the care of patients with lung cancer can lead to greater levels of patient satisfaction (Comer 2000), however, there has been little guidance on the development of such roles or the qualifications and experience necessary to fulfil the role effectively.

In an attempt to identify a current profile of lung cancer nurse specialists and the nature of their practice, a questionnaire was sent to all members of the National Lung Cancer Nurses Forum in August 2000. To register as a member of this Forum, patients with lung cancer must constitute at least 50% of the nurse's caseload.

One hundred and ten questionnaires were completed (response rate 86%).

Data from the survey will be presented which gives an insight to the profile of nurse specialists working with lung cancer patients, their role and areas of satisfaction and dissatisfaction. Implications and recommendations for practice will be discussed.

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The development and role of breast cancer nurses in the USA compared with the UK

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The purpose of this study was to compare the roles and educational preparation of nurses working in breast cancer care in the USA and the UK in order to inform the debate regarding the introduction of specific programmes for Nurse Practitioners (NP's) and Clinical Nurse Specialists (CNS's) in the UK. Neither the NP or CNS has an agreed definition of what the role constitutes leading to variation in educational preparation, experience and clinical remit.

A semi structured interview schedule was developed and these were completed with nurses, surgeons and educators. In the US, three hospitals and two universities were visited in New York and Kentucky, and in the UK two hospitals in the Midlands were used.

Analysis of the interviews provides a rich comparison of the diverse use of nursing titles, the variance in job roles, the education, and the perception of the role by the multi-professional team. The USA has an excellent education programme achieving equity in specialist nurses, but lacks specificity. In the UK there are short specialist courses but no specific programmes for practice at this level resulting in a lack of clarity for patients, nurses and other health professionals. The surgeons were clear that there was a role for CNS's and NP's but expressed concern regarding the lack of methods for auditing performance, the absence of any agreed education programme and the lack of conformity in definition of the criteria to be holding a CNS or NP post.

This study highlights the need to reconsider the spectrum of nursing roles and the need to identify at a national level specific education, skills and competencies that nurses will require in order to practice at this level.

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Communication issues for nurses: What's new on the agenda in the 21st Century?

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Introduction: Over the last decade studies have claimed that effective nurse-patient communication is a high priority for patients with cancer. With a high prevalence of psychological distress in this group of patients nurses are in a key position to assess and alleviate such distress. However, they are inhibited in doing so by poor communication practices and often report feeling stressed by these difficulties. Therefore to be meaningful, communication skills courses need to focus on nurses' perceived difficulties. Aim: The main objective of this study was to assess the areas of communication that nurses feel are important to address. Method: Eight three-day com-

munication skills courses were held across the United Kingdom for nurses in cancer/palliative care. Participants were asked to set the agenda for the three days training. In particular, they were asked to identify specific areas of difficulties experienced with patients, relatives and colleagues. The data was analysed by content analysis. Results: The agendas set by 96 course participants suggest communication skills training for nurses in the 21st Century needs to address communicating with: withdrawn patients; controlling relatives; patients with unrealistic expectations; angry patients; patients in denial; patients' psychological distress; collusion between relatives and health professionals; unsupportive colleagues; patients with sexual difficulties and handling difficult questions. To address some of these issues and to assist with training a new video 'Communication skills course for nurses in clinical cancer care' has been developed which will be demonstrated. The changes in priorities of nurses' perceived communication difficulties with patients over the last decade and the implications of these for training will also be addressed.

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Measuring patients response to received information. Finding out what they want and development of a satisfaction questionnaire

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Background: The benefits of accurate and relevant patient information are now undisputable. As no robust measures of satisfaction exist it is difficult to compare the quality of information provision in response to a new strategy within a cancer unit or between hospitals. The aim of this study was to derive from patients which aspects of information were most important to them and from this develop a questionnaire, which could be used across a cancer network.

Methods: 73 consecutive patients with a diagnosis of cancer, attending the oncology outpatients were asked to anonymously write down up to five most important aspects of information which helped them during their illness and subsequent therapies. Each answer was then read by a multi-disciplinary panel of nurses, doctors and patients and categorised into of groups of similar themes.

Results: 73 patients (24 male, 49 female) returned a total of 303 answers, age range 26-78 years (mean 55 yrs). 38% had breast cancer, 28% bowel, 12% had ovarian and lymphomas as their diagnosis. The mean response per patient was 4 (range 2-5). The answers showed remarkable conformity and could be categorised into 7 main groups as shown below.

1. Side effects/how will I feel 64(87%), 2.Explanation of disease & prognosis 56 (77%), 3.Treatment options and explanations of therapy 55 (75%), 4.Logistical issues (transport, parking, work etc) 47 (64%), 5.Lifestyle issues (exercise, diet, smoking, sexuality) 39 (53%), 6.Follow up/what happens after therapy finishes/genetic risks 25(34%), 7.Support groups, alternative medicine 17 (23%).

Conclusions: From this data a one-page questionnaire has been developed with a 5 point Likert scale for each of these, patient chosen, seven sections. This questionnaire has been used in our network hospitals and has helped us selectively develop our information services. In addition to extra verbal explanation, for sections 1&3 we now routinely use the patient video 'Chemotherapy & Radiotherapy' (available from HEP 02920 40 30 22) and points 3,4,5&7 a hand held file which links to individual files stored on canceret.co.uk. For section 6 we are developing an end of initial treatment video and a family history cancer genetics information video and will use the questionnaire to audit their effectiveness in clinical practice.

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The pain education program: results of an implementation process on nursing wards

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Introduction: Pain is a major problem in cancer patients. In the Netherlands, the Pain Education Program (PEP) was developed as a tailored program in which verbal instruction, a pain brochure and the use of a pain

diary were combined to inform and instruct cancer patients about pain and pain management. The verbal instruction takes 1 - 1.5 hours.

Results showed a significant increase in pain knowledge in patients who received the PEP and a significant decrease in pain intensity. Based on the results we started to implement the PEP in daily practice on nursing wards.

Methods: The aim of the PEP is to improve the pain knowledge and attitude of cancer patients with chronic pain. We wanted the PEP to be integrated in daily nursing practice. All nurses (47) on two medical wards were educated to implement the PEP. In addition, three nurses on both wards were trained as pain-counselors to educate and instruct patients. Pain was assessed in all patients by means of a numeric rating scale and a multidimensional pain assessment. Those patients with a pain duration of at least 1 month were eligible to receive the PEP.

To evaluate the implementation process, measures related to patient, medical and nursing outcomes were collected by means of interview from medical and nursing records.

Results: In total 87 patients received the PEP. Results showed that 74% read the entire pain brochure, 81% used the pain diary, and almost all of them mentioned the PEP as useful.

Of the 36 nurses, 78% reported an increase in pain knowledge, 65% considered they had more skills treating patients' pain using the PEP, and 80% considered the PEP as an important component of pain management. Because of lack of time many patients, who could be included, received no PEP. Physicians reported to have little insight in the effects of the PEP.

Discussion: Nurses showed increased knowledge on pain and pain management. Patients had no problems in using the PEP, they understood the instructions and applied them. However, a number of patients did not receive the PEP, because the nurses had difficulties in implementing the PEP into practice. Therefore, we are formulating a new procedure to improve the feasibility for nurses on the wards.

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Nursing assessment in palliative care: what patients think of nurses' communication skills

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Effective communication must be a two way process (Audit Commission 1993) that engages both the patient and the nurse. Research suggests that in practice communication is less than adequate. To date studies on nurse-patient communication have focused on the nurses' role, and patients have rarely been asked for their views.

Aims: To evaluate patients' perceptions of concerns related to their illness and whether they feel able to discuss these concerns with the nurse. The study also aims to identify any relationship between scores for the nursing assessment and patients' level of satisfaction.

Method: A survey design was used to study the views of the patients and nurses. Data were collected by asking nurses to tape record an assessment interview with a patient. Following the interview the patient completed a self-report questionnaire. The audiotape was scored using The Communication Skills Rating Scale (Wilkinson 1991).

Results: Patients generally felt satisfied with the interaction and felt able to discuss their concerns. They were more likely to disclose physical rather than psychosocial concerns. Findings suggest that disclosure of concerns may be hampered if the patient perceives the nurse to be too busy or if patients feel that their concerns are not pertinent to the nurse. The relationship between patients' level of satisfaction and the rating score was difficult to evaluate effectively because of acknowledged problems with the measurement of patient satisfaction. All patients apart from one felt able to discuss their concerns. This finding may have been influenced by the fact that the nurses in the study had undergone communication skills training and were able to use their skills to obtain a good level of assessment. However, a small number of patients in the study still felt that there were certain concerns that they could not discuss. As patients feel that they benefit from talking about their concerns, it is important that nurses have some understanding of the reasons for non-disclosure. This may ensure that nurses use appropriate communication strategies to enable patients to talk about all their concerns.

Conclusion: Patients in the study were generally very satisfied with the nursing assessment. It is recognised that ascertaining an accurate reflection of satisfaction is problematic. The one patient who felt unable to discuss her concerns was still 'very satisfied' with the assessment interview overall.

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Improving patient information in phase I cancer clinical trials

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Purpose: A particularly challenging area for the clinical research team involved in phase I trials in cancer is that concerned with information giving and informed consent. Patients are at a vulnerable stage in their illness, often experiencing increased levels of anxiety and are faced with trying to understand the difficult concepts associated with early clinical trials. An information booklet for patients was developed in an attempt to address some of these issues. This study reports on the results of the evaluation.

Methods: The booklet is written in a question and answer format. Examples of areas addressed include: What is a phase I trial? Who can take part? Are there any side-effects or risks involved? What if I say no?

The booklet was given to all patients prior to consent. A semi-structured questionnaire was administered, on the first day of treatment, to evaluate patient acceptability and effectiveness of the booklet. Areas investigated included the timing, content, value and volume of information presented.

Results: Sixty-six patients over a period of 30 months were given the booklet with 41 patients (62%) receiving the questionnaire. The booklet was generally well evaluated. All but one patient felt that it should be given routinely to all patients considering participation in a phase I clinical trial. 12.5% reported that the booklet had influenced their decision to enter a clinical trial. Amendments have now been incorporated into the booklet and these will be discussed in the presentation.

Conclusion: The booklet has been shown to be a useful addition to the information available for patients with cancer considering participation in phase I clinical trials. It is now given routinely in the oncology centre to aid the decision making process, enabling patients to give informed consent.

Interactive Symposium

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Empathy in oncological care - an asset or an obstacle?

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For more than 30 years empathy has been a well recognized concept in nursing. It is part of the relationship and communication between nurses and patients with their significant others. Empathy is understood to be appropriate and desirable (Morse, 1992) and is a basic asset in nursing care.

According to Rogers definition (1957) empathy is "... to sense the client's private world as if it were your own, without ever losing the 'as if' quality".

Empathy unifies touch and person-to-person contact (Benner, 1984). Intuition, life-experience as well as higher education may enhance the ability to act and react empathically in supporting distressed patients and families. Empathy makes life in an otherwise highly technical and operationalized therapeutic environment more human. Listening, perceiving and feeling, as well as verbal communication and respect are dimensions of empathy (Reid-Ponte, 1992). In addition to sympathy and compassion, empathic communication skills have become an important part of the educational preparation in basic nursing and even more so in oncology training programs.

Misconceived empathy may be experienced as an obstacle in everyday care. Non-authentic empathy is related to symptoms of burnout. Fear to be too close to the patient is a reality for nurses since the first day of their