

be conducive to effective learning. Large quantities of written information materials have been created to meet the needs of patients with cancer. However, the quality of these materials is often poor. Relevant topics are frequently omitted and treatment options are incompletely covered. Information included is sometimes out-of-date, inaccurate and/or contains a level of bias – in terms of focusing on benefits rather than both benefits and risks. In many cases, patients and their families have not been consulted or involved in the design and writing of educational materials. The patient's and family's ability to learn is influenced by a number of factors including the strength of any prior knowledge and beliefs, degree of stress and anxiety, normal coping style, motivation to learn, presence of cognitive impairment, hearing or sight deficits and the person's literacy level. It is estimated that approximately 20–25% of people in developed countries have a problem with health literacy – the capacity to read, understand and act on appropriate health information. Unfortunately, patient and family education programmes are not always developed with health literacy in mind and are frequently pitched at an incorrect level. Much can be done to optimise patient and family education across a range of different health care settings. The key to good education is to tailor educational programmes to the individual's needs and to employ the principles of clear health communication in all verbal interactions and when developing written/audio-visual materials.

1661

INVITED

#### Developing evidence-based patient education materials

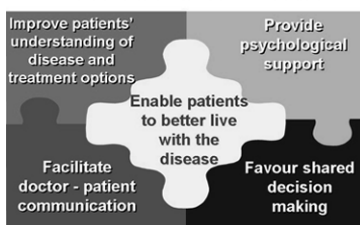
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**Context:** It is increasingly recognised that clinicians are not the only target audience for clinical guidelines. Patients and their family members also want to know more about best practice, including evidence-based standards and treatment options. A review of information materials showed that information is often not evidence-based, inconsistency with patients' needs and present unbalanced view of benefits and side effects. Cancer patients want full information about their condition and the treatment options. Their expressed information needs vary among individuals and depend on the different styles of coping. Information needs centered around different types of information (i.e. research evidence and controversial issues *versus* practical information) according to the different phases of cancer care and disease status (i.e. diagnosis, treatment, follow-up, rehabilitation, remission, recurrent and advanced disease).

**Objective:** The development of good-quality evidence-based patient educational materials is a major challenge to improve quality of care.

**Methods:** Developing booklets and other information packages (video and audio tapes, computer programs, and websites interactive videos...) have long been seen as integral to educational strategies designed to promote health, persuade people to adopt healthy lifestyles, and increase uptake of screening. They have also been developed to educate patients in self care of such chronic conditions as arthritis, hypertension, stress related psychological problems, gastrointestinal diseases, and back pain, and how to take medicines correctly. There is now growing interest in providing information to support patients' participation in choosing treatments and deciding on strategies for managing their health problems.

#### Patient education materials



The SOR SAVOIR PATIENT programme produces well-designed patients' versions of the national guidelines in oncology and education materials. Medical information conveyed by patient guides developed in this program is based on clinical practice guidelines produced by the FNCLCC and the 20 French regional cancer centres, with active participation of specialists (public and private), learned societies and institutions, collaborating in multidisciplinary working groups. These guidelines are used as primary information sources. The development of SOR SAVOIR PATIENT booklets involves 3 steps: (1) the relevant specialist guideline is "translated" into plain language by methodologists, a linguist, and oncology experts; (2) the *knowledge database* produced is adapted to the needs expressed

by patients and families using qualitative methods (focus groups, individual interviews and questionnaires) (3) the final document is reviewed nationally by experts and patients. A professional working group consulted throughout the development of the document validates scientific and medical contents.

**Results:** Failure to provide sufficient information about illness and treatment is the most frequent source of patient dissatisfaction. Studies have found that patients who are well-informed about prognosis and treatment options, risks and benefits of the interventions, are more likely to adhere to treatments. Elaborating patient information with patients themselves is a main quality criteria to provide good-quality materials. Focus groups conducted in the SOR SAVOIR PATIENT programme identified information needs and explored different aspects of information provided (content, language level, form). These materials constitute an important addition to the range of information sources for patients. Importantly, patients were involved at all stages in the development of the documents, greatly increasing the likelihood that the information is relevant, comprehensible and useful. The development of patient decision aids had also to respect standards. They are very different from standard health information materials because they are not didactic or prescriptive.

**Conclusions:** Evidence-based patient materials must actively involve patients to produce easily understood information and satisfy specific information needs. They are to have interdisciplinary input, respect quality criteria's, be appropriate, comprehensive, easy to use and be sensitive to cultural diversity. Evidence-based patient information and educational materials represent a supplement for verbal information in clinical setting. The development of the accessibility to these materials is essential if patients are to understand the treatment options they face and if they are to participate in decisions about their care. The booklets could be used in conjunction with a shared decision-making programme.

1662

INVITED

#### Harnessing the power of information and communication technologies to meet patients' informational needs

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Worldwide more than 11 million people are diagnosed with cancer every year and in developed countries more than 55% of these individuals are over 65 years. It is anticipated that by the year 2020, 60% of all malignancies will affect this age group. Given the rising number of older adults in society the management of cancer in older people will be an increasingly common aspect of oncology practice. It is well documented that compared to their younger counterparts older people are likely to receive inadequate treatment and care and this situation varies internationally. A number of factors contribute to this situation including the lack of adequate knowledge in relation to management of older people generally including the management of multiple co-morbid conditions. Inadequacies in the care and treatment received by older people with cancer as opposed to their younger counterparts is well documented. These include under diagnosis, ineffective symptom management and lower survival rates. This situation reflects the ageism within society generally but is particularly concerning within cancer care given the demographics of our patients. Despite the significant population of older people with cancer, there is limited research on older peoples' perspectives regarding their cancer diagnosis and treatment further compounding the lack of awareness of the needs of this patient group. This paper will consider emerging information on the needs of older people with cancer and consider the challenges for professionals in providing care for older people with cancer.

1663 Abstract not received

#### Poster session

#### Developing the nursing workforce

1664

POSTER

#### The work of chemotherapy nurses: an ethnography

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This study is designed to explore nurses' attitudes and beliefs concerning the chemotherapy administration process, and what they say and do in practice. There are two elements: first, a questionnaire sent to all nurses who administer chemotherapy in London, England (n = 230; 46% response rate) and second, an ethnographic study of 2 outpatient chemotherapy clinics. This paper will focus on the ethnographic element.

An overall expectation of this study was that factors which facilitate and impinge upon current practice of chemotherapy administration would be identified. An understanding of these factors is needed to ensure that nurses have the educational, emotional and instrumental support to deliver chemotherapy safely.

The study has been designed to enable a holistic exploration of the care of patients during chemotherapy, by gathering data in different ways (participant observation, questionnaires and interviews), framed within an ethnographic approach. Data yielded will provide a clear description of nurses' attitudes, feelings and beliefs on chemotherapy administration and how these impact on their practice.

Data collection has finished and analysis is on-going but preliminary findings indicate:

- Big differences in the specialist knowledge and education of nurses administering chemotherapy
- The ways in which specialist knowledge and education can influence nurses' attitudes, beliefs and feelings concerning administering chemotherapy
- The importance of the context of administration, the composition of the nursing team and work practices in relation to the levels of nurses' stress and how this effects patient care

The findings will be discussed with regard to current literature with recommendations for future practice and education provision.

1665

POSTER

#### The role of the research nurse in the recruitment of cancer patients to clinical trials: providing an equitable service

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**Background:** As a direct result of the NHS Cancer Plan the South East London Cancer Research Network (SELCRN) was established in August 2001 in order to increase the national target of patients recruited into clinical trials to 10%.

Evaluation of the roles of the research nurse within this network will identify of potential improvement in order to ensure, not only that targets are being met, but also that the service provided is equitable.

**Material and Methods:** 10 research nurses (SELCRN) maintained a diary, detailing the work undertaken daily for an initial 2 week period. The time taken for tasks such as clinic preparation, reviewing both follow-up and new patients, CRF completion and telephone calls was recorded. The aim was to capture the broad spectrum of work undertaken and to see if there were any differences in workload that could be attributed to specific tumour types. After the initial 2 week period the diaries will be peer reviewed in order to evaluate if this was a useful tool for future use.

**Results and Background:** An evaluation of the diaries of Research nurses at SELCRN will be presented. The results will highlight.

1. The varied role of the research nurse
2. Any areas which could be expanded in order to improve the service
3. Common/differences in work undertaken by specific tumour sites

**Conclusion:** The evaluation of the data will be used to further define the role of the research nurse with the primary aim of providing an equitable access to research trials. Ensuring research is promoted as a dynamic area in which involved nurses can make a real difference. As research networks maintain a high calibre of staff this will mean that patients will receive the benefit of having a broader choice in relation to their treatment.

1666

POSTER

#### The nursing discharge letter: a fundamental tool to ensure continuity of care

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The nursing discharge letter is a fundamental tool for nurses operating in ward units. At the time of discharge, this letter enables the nursing staff to offer a range of information of use to the patient and their family in continuing the therapeutic programme, in preventing or reducing side effects and/or responding to general healthcare needs. Should the patient be unable to return home or provide for their healthcare needs, whether self-sufficiently or with family help, the information will be directed towards the staff who will take responsibility for the patient's healthcare in specialised healthcare centres or through integrated homecare.

**Methodology:** The overall methodology followed these steps:

1. Definition of a working group as representing as much as possible the needs of the different types of department present in the Institute: the head nurse of a surgical ward, the head nurse of a non-surgical ward, and a representative of the nursing service

2. Creation of two different informatics tools (one for ordinary discharge, one for protected discharge), based on a needs analysis for the nursing staff of the various Divisions regarding the information to be provided at the time of discharge. This information is necessary both in cases of self-sufficient patients and in cases where the patients need home care support or hospital admission.
3. Staff education and training concerning the importance of the nursing discharge letter and the correct use of the tools
4. Implementation pilot phase
5. Modification of the tools on the basis of suggestions and needs which arose in the pilot phase, creating specific "flags" for the requirements and characteristics peculiar to each Division
6. Tools application
7. Assessment of their efficiency by surveying closed clinical records in which the presence of the document and certain characteristics of its completion are determined.

**Results:** As yet incomplete. They will be the subject of the Conference poster presentation.

**Conclusions:** Even though the results are not yet complete, the tangible importance of this tool in the Institute's armamentarium of clinical documentation can be readily attested. Furthermore, it is important to note its positive acceptance on the part of the nursing staff who finally have a tool at their disposal to record the healthcare and nursing information essential to the patient at the time of discharge.

1667

POSTER

#### Training in oncology nursing as post-graduate studies – the Portuguese reality

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The improvements in Oncology as far as prevention, tracking, diagnosis, treatment, rehabilitation and supporting care are concerned have generated the need to train and manage multidisciplinary, multi-professional and multi-sector teams... The work of such teams focuses the individual and in inter-action with the primary, secondary and tertiary sectors and is expected to give appropriate response to problems arising from oncology disease.

The Higher Schools of Nursing Bissaya Barreto – Coimbra, Francisco Gentil – Lisboa and Cidade do Porto – Porto in collaboration with the Regional Oncology Centres of the Oncology Institute Francisco Gentil in Coimbra Lisbon and Porto are aware of this fact and take the responsibility inherent to their function. These Centres have started a partnership for the conception and implementation of Post-graduate Studies in Oncology Nursing. Thus they give some response to the National Cancer plan 2001/2005 and are based on the Core Curriculum of the European Oncology Society (EONS)..

23 meetings, 13 on a nationwide basis and 10 on a regional basis have been held by teaching staff of three state Schools and nurses of the Oncology Institutes.

As a result of these meetings the profile of the expert Oncology nurse has been drafted and the study-plan of Postgraduate studies in Oncology Nursing has been set up. This Study-plan has been credited by the European Oncology Nursing Society (EONS).

The fundamentals of the program are some of the most relevant to understand the oncology patient and to develop some thoughts on the practice, fostering critical analysis and the capability to solve problems according to scientific principles.

The curricular development was supported by a conceptual multidisciplinary, modular structure, open to the organization of contents with the aim to develop skills to care for the person/ family/ groups and community in the oncology area.

The evaluation was supported by the principles of adult pedagogy and enhanced the development of the trainees' skills. Individual and group work about the questions resulting from the lack of nursing care were privileged. The methodology project and the achievement file (portfolio) were some of the strategies used during the training.

The purpose of this paper is to describe the design of a course for post-graduation in oncology nursing at a nationwide level.

1668

POSTER

#### Effective leadership

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The aim of this paper is to describe how strategic and operational leadership is being developed within the Northern Cancer Network to support service/ practice development as well as providing the opportunity