

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 Information included is sometimes out-of-date, inaccurate and/or contains a level of bias – in terms of focusing on benefits rather than both benefits and risks.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.

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INVITED

Developing evidence-based patient education materials

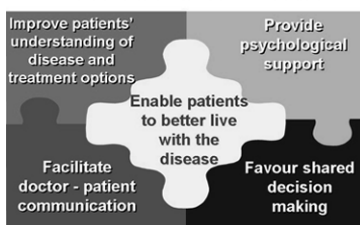
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Context: It is increasingly recognised that clinicians are not the only target audience for clinical guidelines. Patients and their family members also want to know more about best practice, including evidence-based standards and treatment options. 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.

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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

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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.