1116 POSTER

Development of information sources for cancer patients based on clinical practice guidelines and patient needs

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Context: Cancer care and treatment options are highly complex. Much of the available information does not meet the needs expressed by patients, is complex and often is not based on research evidence. As patients increasingly influence medical practice, the dissemination of evidence-based patient information is a major challenge in the implemention of best clinical practice.

Objectives: To develop evidence-based, easily understood and accessible information that meets the expressed needs of cancer patients and family members; to improve patients' understanding of cancer and the treatment process in order to enable them to better participate in their care.

Methods: The project is based on clinical practice guidelines, the "Standards, Options and Recommandations", developed by the Federation of the 20 French Cancer Centres (FNCLCC) and specialists from French Public Universities, General Hospitals and Private Clinics. Guideline development is based on literature review and critical appraisal by a multidisciplinary groups of experts and practitioners feedback. The "translation" of this evidence-based information to laymen is based on a multidisciplinary approach involving specialists in cancer care, nurses, psychologists, linguists as well as patients and family members. The first step consisted in the identification of the specific information needs of cancer patients and their relatives.

Results: The expressed information needs varied among individuals and depended on the different styles of coping. Information needs centered arround 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). Evidence-based information for cancer patients represents a supplement for verbal information in the clinical setting. The methods of access to the information are of paramount importance, both from sources within and without the clinical setting. The current translation of the guidelines into patient information takes account of these findings. To satisfy individual needs, information will be provided on individualized information sheets and touch-screen computers.

Conclusions: The development process has to actively involve patients and family members to assure the satisfaction of individual information needs. Further evaluation will assess the impact on clinical practice of providing patients with evidence-based information.

1117 POSTER

Automated screening and recording of quality of life data: A feasibility study

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Purpose: To evaluate the feasibility and practicality of introducing routine automated methods for assessing the quality of life (QL) of cancer patients into oncology clinics. To assess patient compliance and attitude to routine QL assessment using a computer touchscreen over a six month period.

Method: In a longitudinal study 270 patients from two cancer centres consented to complete the EORTC QLQ C-30 and HADS via a computer touchscreen every time they attended oncology clinics over six months with no additional prompting from staff. Demographic and clinical details were collected for each patient. At the end of the study period patients and staff were sent a questionnaire asking for feedback concerning the study.

Results: Preliminary analysis from one centre shows that compliance at the baseline visit was 95%. At time two compliance dropped to 60% and subsequent visits averaged 35%. Full analysis of data from both centres is on going. Feedback from patients and staff indicate that most people found the computers easy to use and acceptable.

Conclusion: Preliminary analysis suggests that 'oneoff' screening can be undertaken in oncology clinics but that patient compliance quickly falls off over time. This may reflect that the results were not used during the patient/doctor consultation. Data from both centres will be presented as a basis for discussion of the factors relevant to improving the feasibility automated data collection.

1118 POSTER

Evaluation of informations (INFO) received by patients (PTS) in oncology: Comparison between 1995 and 1998 in the same institution

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Purpose: To inform pts is a great challenge, especially in oncology: treatments have a lot of side effects and vital prognosis is often engaged. A prospective survey was performed at Paul-Brousse Oncology Dept in 95, repeated in 98.

Methods: An anonymous questionnaire was used including 36 questions evaluating info about the disease, the treatments, the work-up examinations (radiology, endoscopy, etc) and the organization of the hospital. 144 pts were included in 95 and 101 in 98, all were over 18 years old and in psychological and physical conditions to fill in questionnaires by themselves. Study populations in 95 and 98 were comparable, except for the type of hospitalisation (more pts in day hospital towards full time hospitalization in 98). Statistical analyses were made taking into account this fact.

Results: Knowledge of the disease is essential for 99% of pts. Although there is a significant improvement still 24.5% pts ask for more info (49.6% in 95, $p = 0.0005$). For 91% pts info about chemo and radiotherapy are important and help to a better acceptance of treatments. Info concerning side effects improved (not satisfied 10.3% in 98 vs 26.2 in 95, $p = 0.09$) but 47.9% would like more info. No difference was found concerning work-up examinations (15.7% need more info about purpose). Concerning the hospitalization there is a better identification of the members of the medical team but problems for overall organization.

Conclusion: There is a clear improvement in some key domains concerning pts info. There is a need to better identify pts expectations (qualitative issue).

1119 POSTER

Oncologist's ability to identify patients distress: A survey of 162 cancer patients at the beginning of radiotherapy

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Purpose: Patients show emotional distress, particularly those undergoing radiotherapy. Psychosocial support should be offered to severely distressed patients. This study investigates oncologists' ability to identify patients suffering severe distress.

Methods: In a series of cancer patients, distress was assessed at the beginning of the radiotherapy using the HADS. Simultaneously, oncologists estimated patient distress and their need for psychosocial support by means of a short questinonnaire.

Results: 11.8% of the patients suffered severe, 25.4% moderate, and 62.8% mild distress. Using the lower cut-off values to detect moderate and severe distress (HADS total score > 12), oncologists identified 43 out of 57 "cases" (sensitivity = 75%, specitivity = 28%, PPV = 42%). When, however, the higher cut-off values were used to detect severe distress exclusively (>18), only 5 out 18 patients were identified (sensitivity = 28%, specitivity = 90%, PPV = 28%). Oncologist failed to competely to identify male patients with severe depression, whereas they recognized 38% of severely depressed female patients. Oncologists estimations were not influenced by the tendency of the patients to minimize problems neither by their compliance with treatment.

Conclusion: Our results stress the importance of providing more education to oncologists in order to improve their ability to identify patient psychological distress.