

1442

ORAL

### Patients satisfaction with the cancer notebook

N. Fridriksdottir<sup>1</sup>, J. Sigurdardottir<sup>2</sup>, K. Alexiusdottir<sup>1</sup>, J. Elisdottir<sup>3</sup>, A.L. Ernitsdottir<sup>1</sup>, J. Erlendsdottir<sup>1</sup>, B. Johannsdottir<sup>1</sup>, H. Jonasdottir<sup>1</sup>, A.M. Roesegaard<sup>3</sup>, S. Sigurjonsdottir<sup>1</sup>. <sup>1</sup>Landspítalinn-University Hospital, Medical Oncology/Hematology, Reykjavik, Iceland; <sup>2</sup>Landspítalinn-University Hospital, Office of Academic Affairs, Division of Nursing, Reykjavik, Iceland; <sup>3</sup>Landspítalinn-University Hospital, Gynecology, Reykjavik, Iceland

Providing patients with information is important in oncology nursing, yet dissatisfaction with information is a common problem. In order to improve the quality of service, the Cancer Notebook was developed for patients undergoing cancer therapy. It includes a diary and selected information leaflets. Over one hundred leaflets have been developed including specific information regarding services, cancer therapy, side-effects and self-care instructions. All patients undergoing cancer therapy receive a Cancer Notebook with relevant information leaflets provided by the primary nurse.

**Purposes:** To assess patient satisfaction with the content of the information leaflets, delivery of information and its usefulness. Further to compare the agreement between symptoms experienced, self-care activities and information leaflets received.

**Method:** Of 93 eligible patients who received the notebook from march-december 2000, 69 participated in a structured telephone interview to complete a questionnaire on side-effects, symptom distress, self-care activities and satisfaction with the content of the Cancer Notebook.

**Results:** The sample consisted of 52 women and 17 men. Breast cancer the most common diagnosis (40,6%) and the majority had completed treatment at time of study (67%). Mean number of symptoms experienced was 14 and mean number of information leaflets received was 15.

In general the whole sample was satisfied with the Cancer Notebook. High satisfaction with information leaflets on treatment and side-effects was reported by 60% and 65% respectively. The majority found the information useful (94%) but only 40% reported high satisfaction with the personal usefulness of it. Furthermore only few reported lack of information leaflets (26%) or having sought information elsewhere (20%). Verbal information was reinforced by the leaflets, with half of the sample (54%) and 46% were highly satisfied with it. The notebook itself was used by the patients to record important timings (53%), questions (28%), own well-being (26%) and test results (17%).

**Conclusions:** Cancer patients seem to value the Cancer Notebook. Written information and yet individualized, is particularly important in today's health care delivery, however the method of providing written mate-

rial needs to be considered. Simply handing out leaflets without appropriate verbal information does not improve the quality of service. The results support further development of the Cancer Notebook and methods of giving information.

1443

ORAL

### Monitoring head and neck cancer patients after surgery at home by using information & communication technology

P. Elswijk-de Vries<sup>1</sup>, H. de Graaf-Waar<sup>1</sup>, R.J.J. van Boxtel<sup>1</sup>, C.C.D. van der Rijt<sup>1</sup>, G. Stoter<sup>1</sup>, P.W. Moorman<sup>2</sup>, J.L. van den Brink<sup>2</sup>. <sup>1</sup>Rotterdam Cancer Institute/University Hospital, Medical Oncology, Rotterdam, The Netherlands; <sup>2</sup>Erasmus University, Medical Informatics, Rotterdam, The Netherlands

**Introduction:** Previous studies in Head and Neck (H&N) cancer patients have shown numerous bottlenecks in the transmurals care process. After discharge from hospital following H&N-surgery, most patients have a considerable need for social support, and suffer from feelings of insecurity and uncertainty. Due to a lack of communication between professionals in hospital and in primary care possible problems often remain unnoticed in the period between discharge and the first visit to the outpatient clinic. To improve transmurals oncological care for H&N cancer patients we started a study in which the patients have the opportunity to communicate electronically with the hospital based support team (HBST). Furthermore all involved professionals communicate electronically.

**Methods:** After discharge, patients have a laptop at their disposal for 6 weeks in their home environment. Prior to discharge, patients are informed about the project and receive instructions how to use the laptop. The laptop gives patients access to an information system with four functions: communication, information, contacts with fellow sufferers and monitoring. Monitoring means that patients fill in an electronic questionnaire. If answers are given pointing to possible problems the system sends an alert (e-mail message) to the HBST. One of the clinical nurse specialists (CNS) of the HBST will then act following a written protocol. The CNS creates a message within the system after each patient contact.

**Results:** So far, 24 patients were asked to participate in the study, and 16 included. All patients proved to be able to use the system, which they judged very positively. All patients used the system more than once a week, 67% almost every day. Health care providers who used the system were CNS, H&N-specialists, GP's and speech therapist. When patients returned the laptop, all were glad having participated in the project. The possibility of having contact with the HBST seems to improve their feeling of security.

## Interactive Symposium

1444

### Ethical aspects of cancer prevention

K. Magnusson. Sahlgrenska Universitetssjukhuset, Department of Oncology Research Nurse, Göteborg, Sweden

The best way to prevent cancer is to completely avoid exposure to carcinogens and to reduce the risk-taking behaviour, e.g. ultraviolet light exposure and fat intake. However, since this is nearly impossible for people living in a modern society there is a need for programs for cancer prevention.

Primary cancer prevention is defined as the effort to prevent the development of cancer through health promotion and risk education including behavioural modifications. Secondary cancer prevention includes cancer screening that is a strategy to detect cancer early, before it is clinically apparent. Early detection and treatment of asymptomatic cancer can reduce cancer morbidity and mortality. Recently, another form of secondary cancer prevention have been implemented including screening for genetic or molecular markers, markers that place a person at higher risk for developing a cancer disease.

We already know a lot about cancer prevention and early detection but while there has been attention to the economic and health implications little is still known about the impact on psychosocial responses and ethical aspects. The possibility for predictive genetic testing, for instance, creates

additional problems. What do people want to know about their risk profiles? Who should get access to this information beside themselves? A number of psychosocial and ethical aspects are of importance during the whole process of cancer genetic counselling.

One major challenge for the health care professionals is to develop and refine strategies for communication cancer risk information, among other things.

This presentation is aimed to present ethical dilemmas and psychosocial issues of cancer prevention, especially in connection with cancer genetic counselling.

1445

### Cancer prevention and the impact on the family organization: gene testing as an example

E. Murphy. Division of Oncology, Department of Medicine, University Hospital of Geneva, Switzerland

Progress in the field of genetic counselling in oncology is illustrated by the possibility of gene testing allowing to identify cancer-predisposing genes in a certain number of families. This new approach implies that asymptomatic individuals will be identified as carriers of predisposing genes and