

1442

ORAL

Patients satisfaction with the cancer notebook

N. Fridriksdottir¹, J. Sigurdardottir², K. Alexiusdottir¹, J. Elisdottir³, A.L. Ernitsdottir¹, J. Erlendsdottir¹, B. Johannsdottir¹, H. Jonasdottir¹, A.M. Roesegaard³, S. Sigurjonsdottir¹. ¹Landspítalinn-University Hospital, Medical Oncology/Hematology, Reykjavik, Iceland; ²Landspítalinn-University Hospital, Office of Academic Affairs, Division of Nursing, Reykjavik, Iceland; ³Landspítalinn-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 Vries¹, H. de Graaf-Waar¹, R.J.J. van Bortel¹, C.C.D. van der Rijt¹, G. Stoter¹, P.W. Moorman², J.L. van den Brink². ¹Rotterdam Cancer Institute/University Hospital, Medical Oncology, Rotterdam, The Netherlands; ²Erasmus 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

known to be at high risk of developing cancer. Prevention and surveillance measures, although with their actual limitations, are indispensable in this specific population.

Information process between medical and nursing team and each member of those families generates numerous ethical and psychological questions. As a matter of fact, this information can be taken as a gain or a burden inside a family and several reactions can be observed, from denial to exaggerated demands for screening procedures, and will be illustrated by examples from our genetic counselling consultation.

Motivations and expectations towards genetic testing should be discussed with each individual and his or her choice has to be respected, although it could impede the identification of a cancer-predisposing gene inside a family, such as in the case of an affected member refusing gene testing.

Impact on the family system is probably connected with pre-existing ways of dealing with everyday's events. Identification of psychological patterns that modulate the ability of coping with the knowledge of an heritable risk within the family will help medical and nursing teams' provide an adequate support to all the family members presenting a familial cancer syndromes.

1446

General dilemmas in risk assessment

G. Wigbout. *The Netherlands Cancer Institute, Amsterdam, Netherlands*

In the last decade enormous progress has been made in identifying families with possible hereditary cancer syndromes. Hereditary Breast/Ovarian Cancer and Hereditary Non Polyposis Colorectal Cancer are two of the family cancer syndromes most frequently seen today.

One can ask whether knowledge of this is always a positive development for the consultees and their family members. Questions come to mind such as: Can we offer them total prevention? What price do they have to pay? Is preventive surgery actually a good option? What are the personal and social effects? And last, but not least, how will society respond to these issues in the future. Will it still be possible to get a job, insurance or mortgage?

In this presentation the most prominent dilemmas will be discussed. I will also present the results of a so called "No Show Study" in The Netherlands Cancer Institute, a study of 48 women who declined genetic counseling. There is always the question: do people really want to know more about their increased cancer risk?

1447

Opportunities and burdens for nurse-midwives working in primary health care: Empirical study of the role of the nurse-midwife in population-based cervical cancer screening in urban Sweden

C. Widmark^{1,2}, C. Tishelman¹, E.-L. Lundgren¹, A. Forss^{1,2}. ¹ Karolinska Institutet, Dept. of Nursing, Stockholm, Sweden; ² Karolinska Institutet, IHCAR/Dept. of Public Health Sciences

Background: In Swedish public health care, nurse-midwives have traditionally had a strong and autonomous role. They are main providers of both antenatal care and contraceptive counselling and, also take Pap smears in the population-based cervical cancer-screening program directed to all women aged 23-60. Screening may be a sensitive situation, involving both the risk of a potentially life-threatening sickness and an intimate physical examination that touches upon ideas and assumptions concerning the body, sexuality and norms and values about womanhood. Purpose: Within a larger project investigating cervical cancer screening from the perspective of different actors (lay and professional) various sub-studies have been conducted. The study presented here aimed to explore how nurse-midwives viewed issues such as benefits and risks with the screening, the reliability of the test itself, risk factors for cancer, sources of knowledge/information relevant for cancer screening as well as the manner in which the nurse-midwife described her role in the screening program. Methods: Qualitative semi-structured interviews were conducted with 21 nurse-midwives working with screening in demographically different areas in Greater Stockholm. Results: Results indicate discrepancies between ideals guiding the nurse-midwives and the practice of the screening program. Positive aspects relate to an ideology in which psychosocial care dominates, whereas perceived burdens include factors that prohibit the provision of good psychosocial care, such as lack of time, organisational features, and lack of familiarity with cancer and cancer prevention.

Conclusion: The latent potential of having nurse-midwives work with screening will be discussed, including implications for nursing care and nursing knowledge as means for improving the care provided in the screening program.

Workshop: English

1448

Novel therapies

D. Batchelor. *The Netherlands Cancer Institute, Amsterdam, The Netherlands*

During the last 10 years, research and knowledge in the field of Pharmacology, Immunology and Genetics have contributed to the development of a number of novel approaches that have both cytotoxic or cytostatic working mechanisms. These approaches include (new) cytotoxic agents, signal transduction inhibitors, angiogenesis inhibitors, monoclonal antibody therapy, vaccine and gene therapy. The introduction of these new agents in the clinic have implications for nursing patients in the practice setting and at home.

During this interactive workshop examples of several types of therapy will be given. The agents will be classified according to origin. The principles of their working mechanism will be explained as well as their toxicity and expected results. The practical applications of these agents and specific nursing implications will be addressed. Nurses will be invited to share their experience.

As many of these agents are promising but still early in their development it is not only necessary to ensure the safe administration of these agents but also to be aware of the consequences of the different working mechanisms, unexpected side effects and the nursing care that will be needed to control these side effects. In addition, long term treatment will make it necessary to address issues of compliance, quality of life and coping mechanisms.