tant Clinic and reviewed regularly by Nurse who provides a more holistic consultation. Overall better use of resources.

Conclusion: With the introduction and development of the role of the Specialist Nurse in Urology/Oncology, these patients within this Trust now receive a radically different, more patient-centred and significantly improved quality of care.

1412 ORAL

Evaluation of quality of care for early diagnosed prostate cancer patients treated with brachytherapy and external beam

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Purpose: Improve the quality of care in patients with prostate cancer without symptom of disease in a short admittance period.

Background: A substantional number of patients with prostate cancer (T1-2N0) is treated with brachytherapy followed by external beam. Patients are diagnosed by screening study and are still without disclosure any disease. A few weeks before admission patient history is interviewed by a nurse. During the brachytherapy treatment the patient is admitted for only two days on the ward, a short period of time for the nurse to play an active role to inform and counsel the patient. Because of the characteristics of this patient group (short admission and no complains) we are trying to find an effective way to care for these patients, from a nurse perspective.

Methods: Literature was studied and a questionnaire was developed. The questionnaire included satisfaction items like information received and nursing care/counseling and the need for after-care.

Results: Twenty-five patients were questioned by telephone after their admission. Patients treated for prostate cancer T1-2N0 who do not manifest any sign of disease need specific nursing care.

Conclusion: The analysis of data gives a clear view of patient's information needs. The conditions and possibilities for after-care telephone call, as a method for nurses to evaluate their quality of care will be presented.

1413 ORAL

The knowledge of young men about testicular cancer and their attitudes toward it

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Purpose: Testicular cancer is a rare but serious disease. In the last decades, the incidence of testicular cancer is increasing. In 1993, 59 new cases of testicular cancer were diagnosed in Slovenia, and in 1997, 77 cases. The disease most often affects young men between the ages of 20 to 35, when they are in their reproductive phase of life. That is why this disease and its treatment has such an impact on their emotional, financial and psychosocial aspect of life. Primary goals of this research were to find out how much young men know about testicular cancer, what are their attitudes toward testicular cancer, to what extend they know and perform testicular self-examination, and how much they are motivated to increase the knowledge about this subject.

Methods: Forty-two young men, who served the army, participated in the research. Research data were collected by questionnaires of 30 questions. Questions were arranged in six thematic groups: demographic data, previous experience with cancer, knowledge about testicular cancer, attitudes toward testicular cancer, acquaintance with and performing of testicular self-examination, and motivation. After returning the questionnaire, every participant received a leaflet with information about testicular cancer and testicular self-examination that was published by Slovenian Oncology Nurses Section. The attitudes were measured with the help of the five category Likart scale.

Results: The filled in questionnairs were returned by 98% of participants. The age of the respondents ranged from 20 to 27 years with mean age of 22. The education of the respondents was as follows: 7% finished primary school, 69% secondary school, 17% college and 7% had university degree. None of them ever had cancer, and 83% of them knew someone who had cancer. The results showed insufficient knowledge of participants about testicular cancer; 46% of respondents had positive attitude toward testicular cancer issues, 31% had neutral attitudes, 68% of participants have already heard about testicular self-examination and 29% of them also performed it. Ninety percent of respondents were very motivated to expand knowledge about testicular cancer and 93% about testicular self-examination. The main source of information about testicular cancer and self-examination were the media, rather than the health professionals who played only a marginal role.

Conclusion: The results of this research are similar to the results of other studies. The findings indicate that the majority of respondents were uninformed or misinformed about this subject. This calls for the designing of educational programs for health professionals and of health education programs for young people that should be performed within the regular preventive health care check-ups, in secondary schools, in colleges, and in the army. This could increase awareness of the testicular cancer risk and might improve the cure rate in patients with testicular cancer.

Interactive Symposium

1414

Participation in clinical trials: patient experiences

K. Cox[1], J. Carmichael[2], V. James[1], E. Wilson[1], L. Osbourn[2], K. Clayton[2], S. Asif-Suleman[2], K. Newcombe[2], T. Williamson[2]. [1] *Faculty of Medicine and Health Sciences, Postgraduate Division of Nursing, Nottingham, United Kingdom;* [2] *Nottingham City Hospital NHS Trust, CRC Academic Department of Clinical Oncology, Nottingham, United Kingdom*

This presentation seeks to outline part of a programme of research which concentrates on examining patients and their families experience of cancer clinical trial participation. Clinical trials in cancer raise unique ethical and practical problems. Phase I and II trials involve drugs with an unknown potential to bring about benefit, or indeed harm. Phase III trials raise issues around randomisation and treatment being determined by chance. At the same time there is a social and practical need to continue to recruit people into these trials in order that new treatments can be evaluated. If society and science wish to carry out clinical trials in populations of cancer patients then it is essential that the processes involved are acceptable to patients and based on the ethical principle of respect for persons. This demands that the patients' perspective be incorporated into the management of clinical trials.

This discussion presents two key studies which form part of a programme of work which seeks to examine the patients perspective with regard to cancer clinical trial participation. The first is a longitudinal qualitative study of trial participants experiences and the second is an intervention study which builds on the earlier work and takes the evidence derived from consumer experiences to shape and develop cancer services. Key findings and issues which have arisen from this work will be highlighted and discussed.

1415

The challenge of informing patients

C. Böhme. *Kantonsspital, Internal Medicine, Oncology, St. Gallen, Switzerland*

The aim of this presentation is to point out the challenge of informing patients and to discuss which problems nurses face when performing this task. Informing cancer patients is one of the daily tasks of a nurse working in the oncological field. The need for more information has increased in the past years. Patients and their relatives make use of additional information

technologies like internet, CD-Roms and video recordings. Many medical reference books are published for non-health care providers.

When a patient is offered the possibility to participate in a clinical trial, the healthcare professional must take into consideration not only the stage of the patients' disease and the treatment history, but also the type of study (Phase I, II or III) and its focus e.g. toxicity, therapeutic benefits or supportive care treatment. Information must be given in a clear and correct manner according to GCP norms.

Most of the information patients receive about treatment options, especially in the case of a clinical trial, is provided by a physician, usually an investigator or a co-investigator. It is not always current practice that nurses are involved in the information process about a study.

This presentation will focus on:

- the role of nurses in the information process;
- how nurses react to this challenge;
- which problems nurses face when patients are assertive or do not want any information.

Encouraging patients to actively participate in decisions regarding their treatment is a challenging task and requires precise skills. By using a personalised approach and clear communication methods, nurses contribute to the maintainence of the balance between research interests and patients' needs.

1416

Informed consent forms: what is the impact?

C. Molin. *Karolinska Hospital, Dep. of Oncology, Radiumhemmet, Stockholm, Sweden*

Clinical trials are an essential part of the process of developing new and better cancer therapies. For trials involving human subjects, respect for the individual patients' autonomy requires that research subjects give their informed consent. In obtaining and documenting informed consent, the investigator should comply with the applicable regulatory requirement(s), and should adhere to GCP and to the ethical principles that have their origin in the Declaration of Helsinki. While there is a general consensus on the need for informed consent, there is still an unanswered question on how to achieve a meaningful informed consent. Many factors have an impact on the comprehension of informed consent information. Part of the process for providing the necessary information has been the use of written information and consent forms prior to participation in a clinical trial. The value of this approach has been questioned by some studies which highlight the difficulties that patients have recalling this information while others have focused on the problem of the readability of the forms. Research has showed that consent forms are often written at a scientific level that is too difficult for most study participants to comprehend. The content of consent forms consists of advanced medical technologies, study design, potential risk considerations, legal and regulatory issues, institutional practices etc. The amount of information as well as the complexity affects the readers ability to understand the information given and can be a barrier for the informed consent process.

Literature supports that simplify, can improve readers' comprehension of written materials. Patient reading levels can be assessed. Nurses who participate in developing written information must begin to recognise the diversity of skills and to implement measures for assessing readability. The process of informed consent is a communication process through which nurses can help patients to understand the information. It is imperative that nurses explore novel approaches to communicate cancer clinical trial informed consent information in a understandable manner to enhance effective patient decision-making.

1417

How can education improve the supportive role of the nurses? The core curriculum for cancer clinical trials and the manual for research nurses

P. Di Giulio[1], A. van Wijk[2]. [1] *Istituto Mario Negri, Rivista dell' Infermiere, Milan, Italy;* [2] *NDDO Oncology, Amsterdam*

Many authors emphasize the importance of the staff nurse being knowledgeable about the research and the research process. Nurses, when asked to rank six proposals that would be helpful in increasing knowledge in order to participate in clinical trials listed courses (73%), seminars (67.6%), practical training (60.4%), symposia (50.5%), newsletters (44%) and brochures (36%). Nurses involved in cancer clinical trials have to be aware of the various roles they are expected to perform: participate in the informed consent process, educate patients and staff, provide direct care support to the patient and family, administer drugs and collect data on toxicities, act as patients' advocate, coordinator and administrator, and should be educated to perform them properly. The offer of educational opportunities for nurses involved in cancer clinical trials varies from country to country. Two educational initiatives will be presented.

The Core Curriculum for Cancer Clinical Trials, prepared by the Oncology Nurses Group of the EORTC aims at improving nurses' knowledge of the principles, methods and conduct of cancer trials. The core-curriculum provides a framework on which to design courses to train nurses to participate in cancer clinical trials, and for caring for the trial patients.

The Manual for Research Nurses, written by members of the Early Clinical Studies Group Research Nurses aims at providing research nurses with a handbook together with a reference book. The main objective of the manual is to assist (new) research nurses in understanding the processes and procedures of planning, initiating and monitoring clinical trials. The manual describes theoretical and practical knowledge about clinical trials and their performance and is useful for daily research nursing practice as well as for courses in research nursing.

Providing oncology (research) nurses with adequate knowledge will improve their proficiency as members of the clinical research team. This will improve both the care for patients participating in clinical trials and the quality of data collected.

Workshops

Workshop: English

1418

Altered body image – Nursing interventions for image enhancement

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Many written resources have been published to assist the patient and the caregivers in coping with an altered body image, experienced during and after cancer therapy. The various degrees of psychosocial distress is well known and often discussed. The practical aspects though, are not often incorperated within the provided information.

Developing new programs, influencing changes in existing models to enhance the patients changed body image and therefore promoting quality of life, can and should be encouraged.

Purpose and Aims: The purpose and aims of the workshop will be to enable nurses to:

- identify high risk patient populations.
- review the nursing role in helping the patient set reatlistic goals toward enhancing their outward appearance
- actively practice a few simple, cost containing interventions which are applicable anywhere in the world, and
- inform healthcare professionals about current information resources