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ORAL

Assessment of fatigue and care needs in Turkish women with breast cancer

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Purpose: This research project was planned to determine the level of fatigue experienced by breast cancer patients undergoing chemotherapy and the factors affecting this fatigue level to prepare a guide for the planning of effective nursing care for these patients.

Methods: The research was carried out between July 1999 and May 2000 at the Chemotherapy Department in Institute of Oncology at University of Istanbul with 90 breast cancer patients. To assess the level of fatigue and factors affecting it a Patient Information Form, the Multidimensional Scale of Perceived Social Support scale, the Piper Fatigue Scale and the Rotterdam Symptom Checklist (RSCL) were used and reliability tests were done. It was detected that the scales are appropriate tools for breast cancer patients.

Results: An assessment of the personal characteristics of the patients revealed that 58.9% were between the ages of 30-49, 23.3% were obese, 76.7% were married, and 64.4% were housewives. Assessment of the illness-related characteristics revealed that 67.8% of the patients were in the early stages of the illness, 84.4% had had a previous operation, 83.3% had not received radiotherapy in the acute phase of the illness and 92.2% were using doxorubicin as their chemotherapeutic agent. When pre-treatment and post treatment physical symptoms were compared, the ones showing the greatest increase were, in this order: fatigue, nausea, anorexia, vomiting, constipation, depression and hopelessness about the future, and diffuse fear.

Conclusion: In conclusion, it was determined that breast cancer patients undergoing chemotherapy experienced moderate level of fatigue ($\bar{x}=4.74\pm2.05$), which was influenced by income level, marital status, disease stage, the Karnofsky Performance State score and perception of health. There was, however, a positive correlation between fatigue and the symptoms experienced as a result of chemotherapy treatment. These symptoms increased the level of fatigue and affected quality of life. For this reason, the patient should be followed carefully and given adequate education, in order to keep the symptoms under control. The fatigue associated with breast cancer patients undergoing chemotherapy treatment can only be prevented through individual follow-up of patients and through keeping the treatment-related symptoms under control.

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ORAL

Attitudes towards discussion about sexuality related issues with patients

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Purpose: Aim of this study was to evaluate how often patients discuss about sexuality related issues with hospital staff and how important they consider this kind of discussion.

Method: A questionnaire with 19 questions was given to 300 persons (doctors, nurses, radiotherapists, physiotherapists and social workers) working in departments of oncology, internal medicine, gynaecology, urology or neurology. A different questionnaire with 22 questions was given to 460 patients in same departments.

Results: 215 staff persons (72%) returned the questionnaire. 158 patients (34%) answered, 96 (61%) of them were cancer patients. Malignant disease or its treatment had effected on sexuality in 63% of patients. 73% of cancer patients considered the discussion about sexuality related issues important, 22% of them (mostly breast cancer patients) considered it unimportant and 5% did not express their opinion. Respective figures for patients with non-malignant diseases were 51%, 40% and 9%. Majority of patients (87%) thought that doctors or nurses should make the first question. Only 4% of patients in the department of oncology thought that they would start the discussion by themselves. Patients considered that the main reason why hospital staff haven't discussed with them about sexuality was the lack of time.

63 staff persons (95%) of the department of oncology regarded discussion about sexuality related issues as a part of their work. However 59% of them answered that they discuss about sexuality related issues with less than 10% of their patients. 34% had started discussion on their own initiative and

the rest only when the patient asks. The main reason not to discuss more often is lack of education (50% of doctors, 62% of other professionals).

Conclusion: In spite of a low percentage of patients responses, many cancer patients need information about sexuality and want to discuss sexual matters with their doctors or nurses. The most important reason not to discuss about sexuality is the lack of education not lack of time. Every staff person should be able to make the first question on their own initiative.

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ORAL

Identifying difference in quality of life in men with urological cancers

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Purpose: This study set out to explore the physical and psychosocial impact of radical pelvic radiotherapy for men undergoing prostate and bladder cancer treatment and its subsequent impact on quality of life.

Method: This study combined quality of life data from 2 projects, an initial qualitative study (n=33) and a longitudinal RCT (n=115). Data were collected in the first study using semi-structured interviews, at different cross sectional time points of treatment. In the second study data were collected longitudinally using detailed symptom assessment and the EORTC QLQ-C30 questionnaire at the beginning of radiotherapy treatment, 6 weeks and 12 weeks from start of therapy. The sample in the combined studies was of men undergoing radical radiotherapy for prostate (114) or bladder cancer (34).

Results: Men demonstrated high levels of functional and emotional well being throughout the time of radiotherapy despite symptom occurrence and the onset of acute side effects. Subtle but important differences in quality of life were identified between the two groups of men. Qualitative data yielded information on men's beliefs about their disease and subsequent treatment and raised possible explanations for the high global scores of quality of life in men with prostate cancer.

Conclusions: Quality of life is an important issue for men with urological cancer as side effects of treatment are often considered alongside cancer therapy's impact on quality of life. As a measure quality of life is often used to help decide therapeutic options. Therefore understanding the utility of current quality of life measures in different patient populations is important for health care. Generic measures of quality of life characterise patient experiences in broad terms, allowing comparisons across patient groups, but it appears insensitive to some significant effects of urological cancer treatment.

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ORAL

Improving the quality of service for patients diagnosed with a urological malignancy

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Introduction: Patients with a urological malignancy deserve the highest quality of care throughout their cancer journey. Traditionally, in the author's opinion, patients are often denied of the most efficient and effective care at this most vulnerable and sensitive time. By introducing a Nurse-led Service which concentrates on patients specific as well as overall needs, the author has developed a strategy of care which provides a significantly improved high level quality approach to co-ordinating care from diagnosis, through treatment planning and intervention, and ultimately follow up care.

Patients and Methods: Nurse-led Histology Clinic: Inherently, it is exclusively Doctors who inform patients of their cancer diagnosis. Using the protocols and guidelines agreed by Specialist Nurse and Consultants, patients here receive diagnosis from Specialist Nurse who then co-ordinates further investigations, results and appointments. Subsequently, the patient consultation with Consultant is more productive and meaningful for both patient and Consultant.

Nurse-led Follow-Up Clinic: Patients assessed by Consultants as having stabilised disease are referred to Nurse to co-ordinate follow-up care on their behalf.

Result: Patient questionnaires show overwhelming satisfaction and acceptance. Time to receiving diagnosis halved with co-ordination of investigations, results and appointments allowing for an earlier definitive treatment plan. Patient information is increased and simultaneously patient anxiety reduced.

Following diagnosis a much required but often much neglected continuity of care is provided. Patients are removed from a busy general Consul-

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.

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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 substantial 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.

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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 extent 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 questionnaires 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

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Participation in clinical trials: patient experiences

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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.

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The challenge of Informing patients

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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