Tuesday, 1 November 2005 469

been well documented in cancer support. "Learning to live with Cancer" is an evidence based education and support programme for cancer patients and their significant others and is the result of a scientific research project carried out in Sweden. Psycho-educative group support helps people who have similar problems to act as role models to one another, especially in the use of adaptive coping responses. The implementation of the "Learning to Live with Cancer" programme in ARC Cancer Support Centre in 1998 has been very successful and to date the programme has been completed by over 750 participants. This paper describes the perceived benefits of this course and its implementation in Ireland as a standardized education and support programme for people affected by a cancer diagnosis.

1622 POSTER

#### Are patients interested in clinical trials?

C. Gardiner, L. Woolf. Cancer Research UK, Cancer Information Department, London, United Kingdom

CancerHelp UK (www.cancerhelp.org.uk) is the patient information website of Cancer Research UK, the largest cancer charity outside the USA. The website includes free, easy to understand information about cancer and cancer care. It also includes the only database of UK clinical trials written for patients in plain English. The clinical trials database was launched in November 2000. At that time, providing plain English information about clinical trials for patients was a controversial issue, particularly for early phase trials. We currently list over 200 clinical trials, covering all trial phases, types of treatment and aspects of the cancer journey. Our aim is to include every cancer trial open for recruitment in the UK. Each entry on the database has a summary paragraph explaining the aims of the trial. We also include a list of eligibility criteria, and an overview of what the trial involves in terms of hospital visits etc. Potential patients can use either the simple search (a drop down list of cancer types) or the advanced search (searching by phase or treatment type for example) to find a trial they can take part in. There is also a free text search facility. If a patient finds a trial they are interested in, we advise them to print out the information and take it to their specialist doctor to discuss it further. If they are suitable for the trial, their specialist can then refer them to one of the doctors involved with the trial. Patients' interest in clinical trials has been steadily increasing since the National Cancer Research Institute (NCRI) was formed in the UK in April 2001. Phone and email enquiries about clinical trials were the biggest single category of enquiries to our national cancer information service in 2004. Enquiries about trials have increased by over 300% in the last 3 years. Clinical trials that are mentioned in the media are often among the most frequently viewed. But phase 1 or 2 trials are consistently in the 'top 10', demonstrating the demand for information about early phase trials. The number of trials viewed on the CancerHelp UK clinical trials database now averages over 10,000 per month. This has increased rapidly in the last few years from 4,000 per month in 2003. These figures demonstrate the increasing interest in, and enthusiasm for, information about clinical trials in the UK. It provides evidence of a strong need to provide this information.

1623 POSTER

## Quality of care experienced by Finnish cancer patients during radiotherapy: perspective of background factors

M. Siekkinen<sup>1</sup>, R. Laiho<sup>2</sup>, E. Ruotsalainen<sup>1</sup>, J. Katajisto<sup>3</sup>, H. Leino-Kilpi<sup>4</sup>.

<sup>1</sup>University Central Hospital of Turku, Dpt of Radiotherapy, Turku, Finland;

<sup>2</sup>University Central Hospital of Turku, Dpt of Radiology, Turku, Finland;

<sup>3</sup>University of Turku, Dpt of Statistics, Turku, Finland;

<sup>4</sup>University of Turku, Dpt of Nursing Science, Turku, Finland

**Purpose:** The purpose of this quantitative study was to describe the quality of care during radiotherapy experienced by cancer patients. The ultimate goal of this study is to improve the quality of radiotherapy to correspond with the expectations of patients.

Materials and Method: Data were collected with the Good Nursing Care Scale For Patients instrument (GNCS/P, Leino-Kilpi et al. 1994) modified for this purpose. In this scale, there are four quality categories characteristics of personnel, caring activities, radiotherapy environment and caring process. Patients evaluated the quality on a scale of 1 to 5, score 1 being the best. A total of 134 radiotherapy patients returned questionaires in one university hospital of Finland. Of the respondents, 57% were women and the middle age was 62 years (range 39–81 years). Mainly, the respondent were retired persons. Patients' edication varied, most (68%) of patients had at least some kind of vocational degree. Almost all (81%) were married or living together with someone. The most common type of cancer was breast or prostate cancer.

**Results:** From the view of patients the quality of care was very good. Average values were as follows: characteristics of personnel (1.15), caring activities (1.38), radiotherapy environment (1.42) and caring process (1.37). The background variables were found to have statistically significant

correlations with two sum variables, caring activities and radiotherapy environment. The patients with no professional education considered the activities better than the patients with higher degree (p = 0.001). Patients with no professional education valued the environment higher than others (p < 0.001). The youngest and the second youngest age groups considered the environment worse than the older groups (p < 0.022). Also, employd patients valued the environment and matters associated with it worse than retired patients (p = 0.001).

Conclusions: Quality of care in the radiotherapy was mainly good. The characteristics of personnel were considered best and the least satisfying was the environment. Least satisfied patients were among the youngest, the employed and educated patients. Further planning in quality improvement should focus to guidance with patients and their relatives. The concept of primary nurse and Internet based education should be emphasized.

1624 POSTER

# Patient involvement in the South East Scotland Cancer Network (SCAN): an important component for quality cancer services

L. Norris, M. Murray, A. Gregor, M. MacDonald. South East Scotland Cancer Network, South East Scotland Cancer Network, Edinburgh, United Kingdom

Patient involvement is a key policy supporting health care modernisation in Scotland [1]. SCAN has been actively involving patients in the network since its inception, the first cancer network to do so [2]. The principles of representation, partnership building and focusing on the needs of patients and carers have been at the core of the network's development.

A major building block was development of a shared information base in the Cancer Information Network (CIN). This web-based resource offers real time access to current, relevant quality-assured information to patients, the public and health care professionals (<a href="https://www.scan.scot.nhs.uk">www.scan.scot.nhs.uk</a>). It was built with the active participation of users shaping both content and the look and feel of the website.

The second step was patient representation on disease-specific regional groups, which needed training and development for both patients and professionals. The appointment of a dedicated patient involvement worker was essential for these developments.

Patients have shared their experiences of the cancer journey to a wide audience at SCAN conferences, workshops and events. At the SCAN Communication, Information and Knowledge conference in September 2004 patients had a positive impact through telling two contrasting stories and presenting key communication concerns in a humorous sketch.

A patient-staff review in December 2004 identified good practice and areas for improvement. Good practice includes patient representation on cancer forums in primary care settings, user group representatives participating in strategic cancer planning groups and patient input to education programmes for health care staff. There is now a clear mechanism that supports regional collaboration on patient issues, consistency of approach to quality issues and a regional patient forum.

The ongoing focus is on recruitment of patient representatives, communication and information, and training and support. A training needs assessment has been carried out with one-to-one interviews, questionnaires and focus groups with patient representatives and key SCAN staff informing this process

As a result of these activities, the relationship between patients and professionals in SCAN has grown, bringing strong patient focus to service improvements and providing positive lessons to others embracing this way of working.

### References

- [1] Scottish Executive Health Department, 2001, Patient Focus, Public Involvement, Edinburgh: The Scottish Executive.
- [2] www.scan.scot.nhs.uk

1625 POSTER

A study of head and neck cancer patients' experience of emotional support provided by ward nurses, and nurses perspective of care given

S. Roles. Bristol Haematology and Oncology Centre, Ward 61, Bristol, United Kingdom

Introduction: The in-patient ward of the Bristol Haematology and Oncology Centre has seen an increase in the number of head and neck cancer patients being admitted, due largely to the closure of the hostel that previously accommodated them. This has provided the ward nurses with the opportunity to support these patients at earlier stages of their illness. Work by Rose & Yates (2001) has highlighted the need for better support of this group of cancer patients. Many hospitals have a head and neck Clinical

470 Nursing Programme

Nurse Specialist, who would play a major role in providing emotional support, however, at present there is no such nurse in this Bristol hospital. The ward nurses are in a good position to develop therapeutic relationships with their patients, due to regular contact.

Methods: Over a four-month period, head and neck cancer patients were interviewed in an attempt to discover how well supported they felt at various stages of their cancer journey, specifically by ward nurses. The nurses were also given questionnaires to explore their views regarding how able they felt to support these patients emotionally.

Results: It was found that many patients did feel supported by the ward nurses, while most of the ward nurses felt they could not offer adequate emotional support, mainly due to time constraints and workload. Nurses and patients made suggestions as to how emotional support of the ward may be improved.

Conclusion: Due to the findings of the research, it was decided that the ward nurses should attend a teaching session. This helped them gain a better understanding of the patients needs as well as providing encouragement that many patients did feel well supported already. The head and neck cancer patients care plan has also been updated to include a section of providing emotional support.

1626 POSTER

### Evaluation of the supportive care needs of metastatic prostate cancer patients

A. Quennell, N. Douglas. Guy's and St. Thomas' Foundation Trust, Medical Oncology, London, United Kingdom

Background: In the last 12 months, there has been an increase of patient referrals with metastatic prostate cancer to Medical Oncology for further treatment within our hospital. This is due to the emerging role and benefit chemotherapy now provides these men. This patient group, ranges in age from 37 to 90. They require ongoing supportive care, symptom support, education and palliative care input. At present, no specific support system is in place for these patients.

Material and Methods: An audit of this patient group is being undertaken at present. The audit will collect data in regards to the current support needs of these men, who they are met by, and how they feel that this can be improved. Patients have also been asked whether they would like to attend educational group sessions, on specified topics and/or topics of their choice and to meet together on a regular basis. A proportion of these patients are currently enrolled in a clinical trial, evaluation to see whether their support needs are meet by the Research nurse will be discussed.

**Results:** An evaluation of the audit results of the 60 patients currently visiting the Medical Oncology Department at Guy's Hospital will be undertaken and presented.

Conclusion: The audit has been developed to assess the current support needs of men with metastatic prostate cancer, and to evaluate what support programme/resources need to be developed. We wish to involve these patients in the future development of their care and not to provide what we think is best. Due to the wide age ranges and symptoms of this group of men, we strive to provide a service that is comprehensive to their needs.

1627 POSTER

Quality of life, depression symptoms and informational needs of cancer patients receiving chemotherapy and those of their families

S. Gözüm<sup>1</sup>, D. Akçay<sup>2</sup>. <sup>1</sup>Atatürk University School of Nursing, Public Health Nursing, Erzurum, Turkey; <sup>2</sup>Maresal Çakmak Military Hospital, Erzurum, Turkey

The purpose of this study was to determine the quality of life, depression symptoms and informational needs of cancer patients receiving chemotherapy and of their family caregivers. This article presents findings from a study of 111 patients with cancer and 34 of their primary family caregivers from an outpatient chemotherapy unit in eastern Turkey. The results indicated that the patients perceived a poorer quality of life than their family caregivers. The patients also were more clinically depressed. Furthermore, both the patients and caregivers received little information regarding the illness and the side effects of chemotherapy from their health professionals. Nearly, half of the patients and over half of the caregivers reported that information was given by health professionals was verbal. Most of both patients and caregivers reported that they felt that they need to be visited by health professionals at their home when they ask for such services and/or once a week. Patients reported the need for assistance with one or more personal, instrumental, or administrative activities. Administrative activities need of patients and caregivers were found to be similar. In conclusion, nurses must continue to work hard to focus not only on the disease and its symptoms, but also on the impact on the day to day living of the patient with cancer and his or her family. Home visits may empower patients and caregivers by giving them information and professional support.

1628 POSTER

Women operated for breast cancer – their opinion of follow-up by breast cancer nurse

P. Hanselius. University Hospital UMAS, Surgery, Malmoe, Sweden

Introduction: A study on follow-up 2000–2002 after breast cancer treatment of selected women was carried out at the Department of Surgery, University Hospital UMAS in Malmoe, Sweden. The women were after the one-year follow-up transmitted to a nurse led out-patient clinic, where they taught to examine their breast themselves and where they received a list of symptoms to observe. Simultaneously with the early follow-up by the breast cancer nurse the women had mammography and were informed of the result on the same day.

**Aim:** The aim of the study was to describe how women operated for early breast cancer appreciate the follow-up of a breast cancer nurse two and three years after operation, following the one-year check-up by their physician.

**Method:** The analysis method used was inspired by phenomenography. The method is substance-oriented which means searching for the underlying structure of variance of essence. The point of phenomenographic studies is to describe the variety of conceptions and their prevalence in a well-defined population with respect to the phenomena in the surrounding world. Qualitative semi-structured interviews of 20 women were performed by an independent nurse.

Result: The women's statements were put together in the following three categories of description:

- Reluctance to take responsibility for self-examination.
- Accessibility gives security.
- The possibility for individualisation.

Conclusion: Follow-up after breast cancer treatment by a specially trained breast cancer nurse is a good option for selected women with early breast cancer. The women have confidence in the nurse and appreciate the easy access through her to all members of treatment team.

1629 POSTER

### From a decade ago: a technology trial revisited

P. Bijdekerke, M. Spinnoy, <u>V. Vinh-Hung</u>, G. Storme. *Oncologisch Centrum, AZ-VUB, Jette, Belgium* 

Background: When new technology is introduced, first concerns are efficacy, safety, effect on patients. But also, by definition, before it becomes widespread, new tech is scarce. It might be important to ask what influences its sharing? In a trial 10 years ago comparing radiotherapy simulators, data was collected to evaluate the impact on patient comfort and on workload. The present reanalysis examines the impact on utilization from patient perspective.

Material and methods: Twenty-four patients presenting with early stage uro- or gynecological tumour participated in a non-blinded equally allocated randomized trial comparing simulation, based on integrated CT, versus based on diagnostic CT. Times required at various steps were recorded. A patient self-administered questionnaire was completed before simulation, during transition between simulation itself and CT, and after the whole procedure. Pain, unrest, anxiety and discomfort were assessed on a scale from 0 (no symptom) to 3 (most severe). Analysis was performed by linear models with total procedure time (simulation+CT) as dependent variable. Patient characteristics, allocation and questionnaire scores were examined by stepwise regression.

Results: There were 17 men (15 prostate, 2 bladder, catheterized) and 7 women (4 cervix, 3 endometrium). Mean age was 66 years, Karnofsky status 91.8, weight 78 kg, size 1.7m, blood pressure 156/83. Mean cumulative pain score was 0.3, unrest 2.8, anxiety 1.0, discomfort 1.2. A score >0 before procedure and its persistence after procedure was noted respectively: pain in 4 patients before procedure, persistent in 1 after procedure; unrest in 21 before and 6 after; anxiety in 10 before and 3 after; discomfort in 7 before and 6 after. Mean total procedure duration was 65.4 minutes. By multivariate analysis, factors significantly related with procedure duration were equipment allocation (p = 0.004), gender (p = 0.022), and cumulative anxiety score (p = 0.046). Based on the model retained, the estimated adjusted effects were: a change of equipment reduced procedure time by 11.6 min (different technical performances), gender was associated with a difference of 10.1 min (catheterization), whereas an increase of cumulative anxiety score from 0 to 5 was associated with an increased procedure time of 14.0 min (cumulative score indicated persistence of apprehension throughout the procedure) (Figure 1).

Conclusions: The CTs investigated have been both replaced with faster performing equipment. Nevertheless, the reanalysis emphasizes the