

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?

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CancerHelp UK ([www.cancerhelp.org.uk](http://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

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**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 questionnaires 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' education 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, employed 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

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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 ([www.scan.scot.nhs.uk](http://www.scan.scot.nhs.uk)). 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](http://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

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**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