Objectives:

- To identify research priorities in cancer care informed by patient and carer experiences;
- To develop effective methods of patient and carer involvement, particularly with marginalised groups.

Methods: People affected by cancer are invited via local media to participate in Research Advisory Groups. Respondents are invited to local meetings, co-facilitated by a researcher and a local person, such as a patient involvement worker. To date, Advisory Groups have been established in eight different areas of Scotland, including urban, rural and island communities. In order to involve marginalised groups, work is underway with Chinese people, profoundly deaf people, young people and people in areas of social deprivation.

Participants are asked to discuss their experiences of cancer, cancer treatment and care. Meetings are audiorecorded and transcribed. A summary of each group's discussion is circulated to all the other groups. Data analysis allows us to identify the most important issues for research, in collaboration with the Advisory Groups. Research priorities are identified, so that the Cancer Care Research Centre's work is driven by patient and carer priorities. Centre staff work closely with health professionals, policy makers and the voluntary sector to influence change based on patient and carer experiences.

Results: The work is on-going. By September, we will be able to present a detailed account of the process of patient and carer involvement and initial findings relating to the research priorities identified. We will discuss the methods we are using to engage marginalised groups in the research process. We will be able to discuss the advantages of the methods and the difficulties and reflect on our experiences as researchers and those of the patients and carers who are involved. Ideally, we would like to involve a patient or carer as co-presenter.

1618 POSTER

Systematic literature review about the involvement of people affected by cancer in research, policy, planning and practice

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Background: The Cancer Care Research Centre aims to find out what is known about the involvement of people affected by cancer in research, policy, planning and practice.

Objectives: The purpose of the literature review is to address the following questions:

1. Why people affected by cancer are involved in research, policy, planning and healthcare practice;
2. How are they involved, and
3. What influence does their involvement have?

Methods: The systematic review carried out included a range of literature comprising different types of empirical studies and also non-research publications. Documents were searched for systematically from key electronic health and social care databases, hand-searching and by an internet search. Criteria for including and excluding documents were applied which resulted in the inclusion of 300 documents for the review. A meta-ethnography was adapted to analyse the evidence and an appraisal of the strength of evidence was carried out using quality criteria.

Results: The work is on-going. By September, we will be able to present a detailed account of what is known about the involvement of people affected by cancer in research, policy, planning and practice. We will report on reasons given for involving people affected by cancer, the methods used to involve them and the influence that their involvement has had on research, policy, planning and the practice of care. We will report relationships between espoused reasons for involving people affected by cancer (theory), how they are involved (process) and the influence that their involvement has had (outcome).

1619 POSTER

Nursing for dreams

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Background: this article will not talk about research, nursing studies, literature review, nursing planning, care models. I will not even mention data, statistics, average values. This abstract will not show you anything extraordinary or innovative. It will talk about the nursing for dreams. It does not exist in any nursing theory but comes from an experience in which, thanks to my profession, I was able to realize a big dream which belonged only to a great young woman.

Experience: her name is Emily (it should be more correct to say "her name was" but I like to remember her as if she was present here and listening to me). At the beginning of August 2004 she has been defined terminally ill patient, because of a PNET. The time for her was rolling by upside down: other 3–4 months of life more when the life was exploding in her. Emily's dream was to make a journey in Jamaica as soon as she was feeling better. Her parents and friends realized that this dream was unfeasible but maybe there was still the possibility to do something for her. So on the occasion of her eighteenth birthday, parents, relatives and friends organized an unforgettable holiday at Capo Verde. The necessary of a medical figure was the only one condition imposed by the medical staff. That was necessary both for the management of the analgesic therapy (Emily's pain was harsh and almost continuous, VAS = 8), and for the management of all the possible medical complications which could happened. I have been picked out as medical figure both for my young age and for my good relationship with Emily and my good knowledge of her case and clinical history.

Outcome: this experience has been a concentrate of surprise and difficulty both from a human point of view and from a professional one. The responsibilities and difficulties were not little and I realize in particular now, thinking of them with hindsight, but it was well worth it. In those moments I realized what means to be the first person responsible for a particular choice both from a deontological point of view and an ethical one. I have also touched with my hands the meaning of holistic assistance. The nursing for dreams is a new prospect to which our profession has to yearn for because all our patients, oncological and not, are entitled to see their dreams, small or big, achieved.

1620 POSTER

Understanding the care and support needs of children and young people with cancer – a participatory research study

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Background: How children and young people experience care and treatment and what they perceive as important has received little attention. Previously, the focus has been upon identifying aspects of care from the perspective of parents. In order to provide services that genuinely meet their needs, children and young peoples' views must be sought.

Methods: A descriptive study to explore perceptions of care and support needs was undertaken. Thirty-eight children and young people with cancer aged between 4 and 19 years at different stages of the cancer journey participated. Participatory-based, age appropriate research methods were used to collect data, including play and puppets, 'draw and write' technique, peer interviews, semi-structured interviews and focus groups. Data were analysed using thematic coding.

Results: Through talking about their experiences, participants identified positive and less positive aspects of care. The perception of care and support needs of participants varied according to age. Whereas for younger children their focus was on their immediate needs, such as availability of toys and how treatments limited their activities, older children focused more on issues related to treatment and being involved in decisions. Communication and information were important issues that featured in the stories of all participants.

Conclusion: This study identifies the care and support needs of children and young people from their viewpoint. The findings have implications for services caring for children and young people with cancer. This paper will present the study, reflect on the findings and explore in detail the theme 'talk to me not through me'.

1621 POSTER

"Learning to live with cancer" – the ARC Irish experience!

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Patients react to a cancer diagnosis with a variety of emotions and psychosocial oncology focuses on how the physical manifestations of cancer impact upon the cognitive, behavioural, social and spiritual components of the lives of patients with cancer. Psychosocial interventions aim to alleviate the emotional and social impact of cancer on patients and their families. Information is a basic form of support. Correct and adequate information is essential to helping patient and family adapt to a diagnosis of cancer and develop coping skills. Studies suggest that patients who receive good information are more satisfied with their care and demonstrate lowered levels of anxiety and depression. The role of support groups has 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*) 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 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

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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*). 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

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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