per 100'000 women in 2002. Improvement in the treatment of breast cancer has decreased mortality of the patients, but at the same time fatigue is one of the most frequent and distressing symptoms reported by patients who receive chemotherapy. Fatigue is multicausal, multidimensional and subjective sensation. Thus, the challenge at present is to improve the assessment of fatigue during chemotherapy in order to develop fatigue coping strategies more individually.

The purpose of this study was to describe breast cancer patient's fatigue and fatigue coping strategies during chemotherapy. The fatigue level was evaluated through different aspects: subjective quantification of fatigue, subjective distress because of fatigue, subjective assessment of the effect of fatigue on chores/work and on pastimes/hobbies. In addition, the relationship between demographic and other background variables, fatigue and fatigue coping strategies was studied.

Material and methods: The sample ($n=69$) consisted breast cancer patients of one university hospital in Finland. Inclusion criteria were: female breast cancer patient, chemotherapy, age over 18 years, Finnish speaking, no cognitive disabilities and informed consent. The response rate was 57%. Data were collected in 2004 by three parallel questionnaires. Patients were asked to fill in a health status information form, The Fatigue Diary, Ream et al. 2002 for seven days, and Standard Questionnaire, The Brief COPE, Carver 1997.

Results: The results showed that the fatigue level varied during chemotherapy. Breast cancer patients experienced more fatigue during third, fourth and fifth day of chemotherapy. On the fourth day, patients experienced fatigue and distress the most, and the effect of fatigue on chores/work and on pastimes/hobbies was highest. Patients used different coping strategies. Fatigue and coping strategies seem to be correlate with certain demographic factors. By employment status, patients on sick leave and out of employment were most fatigued. In particular, younger patients used coping strategies less than older patients. Childless patients were more fatigued and used coping strategies less than patients who had children.

Conclusion: The conclusion of this study is that by evaluating fatigue and coping strategies, more information about intermittent fatigue experiencing and coping strategies could be found. The results can be used to support breast cancer patients' individual coping strategies. Qualitative research will be needed in order to receive knowledge of patients' experiences and reasons for the use of certain coping strategies.

1614 POSTER

Internet cancer information: developing knowledge partnerships with patients and families

J. Gilmour. *Massey University, School of Health Science, Wellington, New Zealand*

The Internet is an important information source and support for people with cancer. Distinctive aspects of the Internet include 24-hour contact, individual ability to pace information according to need, and access to wide ranging professional and personal knowledge. There are also significant issues associated with Internet health information. Numerous studies report misleading information, significant information gaps and little reference to evidence based literature on some sites. The abundance of information on the Internet also requires searching and evaluation skills. Yet another issue is the unequal access to Internet resources as use is linked to household income and ethnicity and reflects broader patterns of societal discrimination.

In this presentation a case study is used to illustrate the strengths and the limitations of Internet health information for one form of cancer, along with recommendations and resources for supporting patients and families' effective Internet use. A critical first step is assessing patient and family knowledge at each point of contact. The development of resource sheets detailing appropriate Internet sites for people at different stages of cancer as a starting point for individual searches is also an important aspect of patient education. Short teaching sessions demonstrating effective searching skills may also be necessary.

At an institutional and policy level, nurses can promote freely accessible Internet facilities at strategic sites to enable better access for all people with cancer to this presently unequally distributed knowledge resource.

Nurses, and other health professionals with expertise in Internet resources and information retrieval, have a vital role assisting patients and families to evaluate Internet cancer information. Nurses can also identify information and access gaps and promote initiatives to reduce inequalities in the use of Internet resources.

1615 POSTER

Empathy – the key to quality care

T. Wiseman. *Kings College London, Florence Nightingale School of Nursing and Midwife, London, United Kingdom*

This study contributes to the understanding of empathy by considering its role in nursing practice, and its relationship to the context in which nursing takes place.

An ethnographic approach was used to explore the nature and meaning of empathy for nurses and patients on a 14 bedded, mixed sex oncology ward. Data were generated through participant observation and formal and informal interviews over a two year period; and analysed using a modified thematic analysis.

The findings suggest that empathy allowed nurses insight into the ways in which their patients experienced and coped with illness. Empathic understanding was generally associated with forms of problem solving and care planning that were valued by patients and found to be rewarding by nurses. Four different forms of empathy were identified, representing a continuum of empathy development. Moreover, the findings revealed the importance of the context in which nurses worked with regard to the expression of empathy. Empathy was most commonly expressed when staffing levels were high, nurses practised patient-centred care and were supported by other ward nurses and managers. The implications of these findings are discussed with particular reference to the knowledge nurses develop in practice and the ways in which nurses cope with stress and illness in the healthcare setting. In addition a new conceptualisation of empathy is proposed which enables a deeper understanding of empathy and accommodates the different ways empathy has been conceptualised in the past.

1616 POSTER

Involving patients and carers in the development of an electronic information management tool to support improvements in cancer care

D. Hamilton, L. Norris, E. Murray. *SCAN South East Scotland Cancer Network, Edinburgh, United Kingdom*

Managed clinical networks and new, systematic approaches to information and management are key modernisation components of the National Health Service in Scotland (Cancer in Scotland: Action for Change 2001, National eHealth / IM&T Strategy 2004). The South East Scotland Cancer Network (SCAN) brings together over 600 clinical staff, serving a population of 1.2 million people (from which about 8000 new cases of cancer are diagnosed each year). Working in partnership with patients, SCAN has developed a novel way to promote information sharing and help overcome the challenges of working across geographical, organisational, and professional boundaries. The SCAN Cancer Information Network (*www.scan.scot.nhs.uk*) aims to improve the quality of information for people affected by cancer in the SCAN region by reducing variation and improving the availability of quality-assured resources, including: virtual tours, diagnosis and treatment information leaflets, practical non-medical information, sources of support and web-links. It uses web technology to provide a single point of entry for professionals, patients, and carers to information about cancer and local services. Patients and carer involvement has been essential at each stage of the network's development. Working with the SCAN Patient Involvement Network, a programme of patient involvement is being implemented, including: usability testing; patients and carers ($n=12$) assessed the usability of the network's prototype architecture through one-to-one structured interviews, the outcome of which was a technical development plan to inform the functionality and visual design of the release version of the network; content evaluation; a qualitative research study using paired interviews ($n=16$) analysed the quality of content on the network, and is being used to inform future content development editorial input; a patient information editorial board will provide a forum for evaluating information resources, identifying gaps in information provision, commissioning new resources, and facilitate communication with health care professionals and key information providers. This presentation will reflect on the impact of patient involvement in developing the SCAN Cancer Information Network. It will consider both successes and barriers to effective patient involvement in this context and share lessons learned.

1617 POSTER

Involving patients and carers in cancer care research

A. Worth, N. Rowa-Dewar, N. Kearney, G. Hubbard. *University of Stirling, Cancer Care Research Centre, Stirling, United Kingdom*

Background: The Cancer Care Research Centre is developing methods of involving patients and carers in the research process, with a particular focus on involving marginalised groups who are less likely to become involved.

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

G. Hubbard. *Cancer Care Research Centre, Nursing and Midwifery, Stirling, United Kingdom*

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

M. Bernardi. *Oncoematoly Pediatrics of Padova, San Martino di Lupari, Italy*

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!

U. Courtney[1], M. White[1], T. Fitzpatrick[2], P. Hargadon[1], R. Breslin[3]. [1]*ARC Cancer Support Centre, ARC House, Dublin, Ireland;* [2]*Mater Private Hospital, Oncology Day Unit, Dublin, Ireland;* [3]*Mater Private Hospital, Radiotherapy Department, Dublin, Ireland*

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