patients, respectively. At every sixth week the same questionnaires were filled in until treatment was stopped

Twenty-five of the patients had previously received chemotherapy as adjuvant treatment and 41 patients in the metastatic setting. Eighty percent had a performance status (PS) 0 or 1 at entry, and bone and liver were the most common sites, both individually and in combination, for symptoms from metastases to occur. Median age was 62 (range 33–81). A quarter of the women were treated every week without pause and the rest with a pause every fourth week

**Results:** Fifty-six women were given 816 doses in total with a mean of 16 doses per patient. The most common side effect was muscle pain (30%) and the most common complaint was fatigue (69%). Most women (72%) did not experience any negative influence on social and familial life from the weekly treatment. For those who had had chemotherapy on a three-week schedule before, all but three found the weekly schedule more advantageous especially in terms of fewer side effects and a feeling of secure by seeing the nurse every week. At the sixth week and at the time of next to last dose, 75% and 60% respectively thought their total health was better or unimpaired and scored their QoL higher or equal compared to the baseline. This was in accordance with the nurses report of PS and the patient's total benefit from the treatment

**Conclusions:** The weekly Paclitaxel-regimen is well tolerated, has few side effects and has only a minor influence on the patient's daily life.

**1610** POSTER

### Monitoring and securing quality in oncological care – the 2004 longitudinal PASQOC® results

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The study on Patient Satisfaction and Quality in Oncological Care (PASQOC®) 2002 was the first assessment in Germany focussing directly on patient satisfaction in this therapeutic area. In 2004 PASQOC® was executed again, this time also to assess and observe quality of oncological care over time (2002/2004). Of 49 participating oncological practices and ambulances, 16 were following-up on their 2002 experience.

**Method:** Within a defined recruiting period the validated questionnaire PASQOC® was distributed to all cancer patients presenting at the investigators' practices. Patients' inclusion criteria: German speaking, ⩾18 years, confirmed cancer diagnosis, physical/mental ability to complete a self-administered questionnaire. The questionnaire is analysed by creating dichotomous 'problem scores' indicating the presence or absence of a problem. These are summed into 13 'dimension scores', each clustering a defined set of questions.

**Results (2002 figures in parentheses):** Samples did not differ significantly in structure. The 16 practices recruited n = 1639 patients (n = 1826), 50.9% women (55.0); mean age 63.6 years (62.4). By comparing 2004 with 2002 data it can be demonstrated that 5 practices showed overall improvement in all dimensions, 3 practices improved in some dimensions, 4 practices improved and decreased, while 4 maintained steady state.

**Quality assurance over time:** patients of one practice reported much more problems in all dimensions in 2002 than observed on average. The picture improved in 2004 as the practice presents itself on average with only "praxis organisation" being still an issue for patients (+37%). This practice demonstrated an overall better performance based on improvements in 8 out of 13 scales. Problem scores dropped (ie. improvement) especially in inter-person communication dimensions, ie. patient-physician relationship (−56%), co-management (−32%), involvement of family members (−54%) and discussion with other patients (−41%).

**Conclusion:** Assessing patient satisfaction over time is one tool to generate a platform for quality assurance in oncological care. The PASCOQ® questionnaire is a tool to assess not only status quo but is also feasible to detect changes in patients' satisfaction with physicians, staff, environment as well as side effects and supportive medication. The next step is to discuss and identify the levers that generated improvement with participating practices and ambulances.

**1611** POSTER

### Monitoring importance and satisfaction with patient information: a performance indicator measurement approach

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**Background:** Providing patient information is an integral part of a comprehensive cancer program. Patients' capacity to cope and handle the challenges arising from their cancer diagnosis and treatment is, in large measure, dependent upon their access to information that is relevant to them. Monitoring how well a cancer program is performing its role of providing relevant information, then, is an important quality improvement activity. However, the monitoring activity must take into consideration the burden on the patient and the high workload currently observed in many clinical settings. The tools used to monitor must be easily administered, and scored, as well as psychometrically sound.

**Materials and Methods:** The Cancer Patient Information and Satisfaction Scale is a newly developed reliable tool. It will allow monitoring over time of the importance patients assign to particular topic areas and their satisfaction with what information they received about important topics.

**Results and Conclusions:** Data have been gathered in a regional cancer center on five occasions ($N_1 = 540$; $N_2 = 39$; $N_3 = 2$; $N_4 = 59$; $N_5 = 63$). Internal consistency (Cronbach's alpha) for the Importance Scale is 0.89 and for the Satisfaction Scale is 0.92. Data analysis allowed identification of areas where there are potential problems and further investigation is warranted. For example, women reported lower levels of satisfaction with the information they received than did men. Key to the successful utilization of these performance data is clear and focused reporting and identified accountability for improvements.

**1612** POSTER

### Living with a peripherally inserted central catheter for the delivery of cancer chemotherapy: a phenomenological study

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**Introduction:** Since the implementation of the United Kingdom Central Council's (UKCC) Scope of Professional Practice (1992) nurses have undertaken roles and procedures historically in the domain of the medical profession, one such area has been the insertion and maintenance of peripherally inserted central venous catheters (PICCs). Central venous catheters have been studied in great depth over the last 10 years, however, an area of research that has been significantly overlooked is the cancer patient's experience of living with a central venous catheter.

**Aim of the study:** To describe the experience of living with a peripherally inserted central catheter for the delivery of cancer chemotherapy?

**Methodology:** A descriptive phenomenological approach; following the works of Colaizzi (1978) and Moustakas (1994) was utilised.

**Method:** In-depth focused one to one interviews were conducted with a purposeful sample of 5 patients who had received chemotherapy treatment via a PICC catheter.

**Results:** Five themes emerged from the data; adaptation to the PICC; caring for the PICC; visual indication something is wrong; no problem and the impact of the PICC.

The experience of living with a PICC is inseparable from the cancer experience. The PICC is a life giving entity, it enables one to receive the cancer treatment, and therefore it needs to be cared for, nurtured, protected and respected. Compliance with instructions is expected and willingly given. However the boundaries of compliance are tested in order to maintain a degree of control over ones life. Although the PICC affects a persons' view of themselves it is nothing in comparison to the diagnosis and subsequent treatment for the cancer. It is the reactions of others, the questions, the stares, that cause discomfort and lead to a dilemma concerning disclosing the cancer patient status. One would rather hide the PICC and avoid the questions.

**Conclusion:** The experience of living with a PICC impacts on the individual, however, this cannot be separated from the whole experience of having and being treated for cancer. The concerns of the participants were fundamentally linked to the diagnosis, for example the presence of stigma, altered body image and the desire for treatment success and cure.

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**1613** POSTER

### Breast cancer patients' fatigue and fatigue coping strategies during chemotherapy

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**Background:** Breast cancer is the most common cancer in women all around the world. In Finland, the incidence rate of breast cancer was 84.9

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.