Poster session
Patient's perspectives

1606 POSTER

Patient involvement in oral care during a course of chemotherapy

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Background: This study aimed to evaluate the feasibility and acceptability of a mouth care diary to direct self-care for patients receiving chemotherapy.
Materials and Methods: A consecutive sample of patients (n = 45) with a range of cancer diagnoses from 2 clinical sites in Scotland consented to participate in this study. A mouth care diary was designed to include 2 sections:

– a diary section for daily mouth assessment, using the Oral Assessment Guide (Eilers et al 1988), giving a daily mouth score
– a self-care guide providing structured self-care advice tailored to the daily mouth score.

Patients completed the mouth care diary for 14 days following 2 consecutive cycles of chemotherapy. Patient expectations and experiences of the mouth care diary and their participation in the study were evaluated by means of 2 purpose-designed semi-structured questionnaires: one pre-study and one post-study. In-depth interviews (n = 9) were conducted with a purposive sample of the study population at the end of the study to gain a deeper appreciation of patients' experiences.
Results: 46% of patients approached agreed to participate in the study.
Pre-study questionnaire: Pre-study questionnaires were completed by 42 patients (94% of study population). In general, mouthcare prior to starting the study was good: 67% brushed their teeth twice daily; 53% used mouthwash; 71% attended a dentists either once (40%) or twice (31%) a year. However, 73% felt that their mouthcare could be improved. Their expectations of the project were also positive: 71% felt it would be educational; 58% thought valuable and 27% believed it would be rewarding.
Post-study questionnaire: Post-study questionnaires were completed by 38 patients (97% of the population completing the study). Sixty-two percent of patients believed they had learnt from their involvement in the study. They reported finding the diary: simple to understand (78%); easy to complete (48%) and useful to complete (28%). Seventy-eight percent of respondents found it easy to assess their mouths and assign a daily mouth score, while 74% found the mouthcare advice relevant. Of those who responded, 51% felt that using participating in the study changed the way they cared for their mouth.
Patient Interviews: Patients enjoyed participating in the study and found it helpful for guiding their self-care. However, they could understand that the perspectives of those who declined to participate due to feeling overwhelmed or too ill to take on this additional role. Patients continued to follow the oral care self-care advice despite coming to the end of their participation in the study.
Conclusions: Patients participating in this feasibility study found the mouth care diary an acceptable method of assessing their mouths and ensuring they cared for it appropriately. Those patients who declined to participate were often too ill or overwhelmed by their diagnosis to take part. The mouth care diary is a feasible and acceptable method of encouraging patients to participate in self-care.

References

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1607 POSTER

Cancer patients' informational needs about sexuality related issues

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Purpose: The purpose of this study was to identify and describe the importance of information for patients about sexuality related issues during hospitalization.
Description on the study: 352 patients (288 with cancer) completed the structural questionnaire.
Results: Most cancer patients (72%) reported that their disease or its treatments had affected their sexuality. Men reported slightly more adverse effects of disease or treatment on their sexuality than did women. Effects on sexuality were reported by 78% of men and 66% of women (p = 0.045) having cancer. Among younger cancer patients reported more often effects of disease than did older cancer respondents. Over than half, 76% (n = 50) of respondents under 40 and 66% (n = 152) of respondents over 50 years old complained effect on sexuality. Most cancer patients (71%) stated that it is necessary to discuss about the effect of the disease and of its treatment on sexuality during hospitalization. Most cancer patients (89%) wanted the health care personnel to take the iniative for the discussion of sexuality related issues. Only 11% expressed the wish that the iniative should come from the patient.
Clinical implications: It is important that healthcare professionals provide cancer patients with an opportunity to discuss sexuality related issues. The caring organisation should develop, introduce and evaluate action models to facilitate especially opening discussion of these sensitive issues.
Key words: sexuality, cancer patient, opening discussion

1608 POSTER

A comparison of EMLA cream and/or methoxyflurane for lymphoscintigraphy: A pilot study

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The pain associated with lymphoscintigraphy injection is intense but short lived. We believe that Methoxyflurane may provide an ideal short term pain management strategy for this procedure and furthermore significantly reduce anxiety in this group of pre operative patients.
In recent years techniques have been developed which aim to avoid full regional lymph node removal in patients with breast cancer and melanoma. The 'sentinel' node(s) – the node or nodes to which the area of the tumour drains – is identified and surgically removed. Only those patients in whom the sentinel node contains tumour cells undergo full loco-regional lymph node removal. The sentinel node is identified by injecting radioactive blue dye at the tumour site and tracing back blue lymphatics to the first draining blue node(s).
Unfortunately this procedure can be quite painful and anxiety producing. Current routine practice at our centre involves the use of EMLA cream (a topical cream that contains a local anaesthetic) which is of questionable efficacy. There is a paucity of literature relating to sentinel lymphoscintigraphy and the pain that it evokes.
Methoxyflurane is a volatile anaesthetic agent that produces analgesia at low inspired concentrations. It has a long history of use in relieving pain with minimal side effects. Methoxyflurane analgesia has an important role in short term pain relief in hospital practice as an alternative to narcotics, ketamine, diazepam, or nitrous oxide.
We believe that methoxyflurane would be ideal for the treatment of pain for patients undergoing sentinel lymph node biopsy.
In order to investigate the effectiveness of methoxyflurane in this patient group we plan to compare EMLA cream alone with EMLA cream with Methoxyflurane. We plan to enrol 60 participants. Patients will be randomly allocated to receive the above treatments and have their pain and anxiety levels assessed.
Pain assessments will involve patients evaluating their pain on a visual analogue scale (VAS). Anxiety will be assessed using both the State Trait Anxiety Index (STAI) and a visual analogue scale (VAS).
The data to be presented will include tables indicating differences in pain and anxiety levels between each group of patients.

1609 POSTER

Weekly paclitaxel and Quality of Life in women with advanced breast cancer

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Background: Paclitaxel (P) was previously given only on a three-week schedule in both adjuvant and palliative settings. In recent years weekly administration has been offered to women with advanced breast cancer with the intention to diminish or to avoid side effects such as infections, total hair loss and drug related muscle pain. Data from several studies has shown an effect with weekly doses comparable to treatment on a three weeks basis.
How does a weekly administration influence quality of life (QoL) in women with advanced breast cancer in terms of side effects and interference with familial and social life?
Material and Methods: A non-interventional prospective QoL study. Women at any age with advanced breast cancer who where offered weekly P by their physicians, were informed about the study and 58 women agreed to participate. Baseline information about previous treatment and PS as well as QoL before the start of P was obtained from nurse and

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