3626 POSTER

Communicating Risk in Familial Cancer: the European Patient Perspective

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Background: Breast cancer is the most common cancer in women worldwide. 5−10% of these breast cancers occur in women because of an inherited mutation. Genetic testing can establish if a person is at increased risk of breast cancer. The term 'risk' in relation to familial cancer can have multiple meanings for both clinicians and patients. Failing to identify and address this may impair effective communication and informed decision making and adversely affect the quality of patient care.
Methods: 6 participants took part in a Round Table Discussion (RTD) exploring the information needs of people with a genetic risk of breast cancer, at the 2010 European Breast Cancer Conference. 4 participants had had breast cancer, 2 with a BRCA mutation; all had links with advocacy organisations and brought their own perspectives and the experiences of others. 2 participants were health care professionals with expertise in cancer communication and medical genetics. Additional comments from two other BRCA affected women who reviewed the video clips were used to complete the data set along with the transcribed RTD.
Results: The central issues that emerged were:
- Decision Making: participants discussed the implications of different choices and offered emotional, cognitive and considered reasons for their own preferences.
- Information and support needs: these change at different stages through the 'genetic cancer journey'.
- Skills of communicators: participants highlighted the importance of good communication in conveying an individual's risk, and the need to consider pre-existing attitudes, beliefs and health literacy.
- Telling the family: a concern was the role of patient as information giver, when required to 'tell the family' of their genetic status with what they felt to be inadequate tools or support.

Conclusions: Communicating cancer risk effectively has the potential to aid individuals in making informed decisions about their health and health care choices, reduce adverse psychological and social consequences and motivate high risk individuals to participate in cancer prevention and surveillance protocols. Capturing experiences in different settings allows us to share good practice on a European basis.
There is still a need to understand the changing information needs of patients and families with time and circumstance, and to ensure that the ability of individuals to make informed decisions are understood by health professionals involved in the communication of risk.

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European Cancer Guidelines: a Survey

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Background: Cancer guidelines (CG) are used to optimize cancer screening, diagnosis, treatment and care. The aim of this survey was to create an inventory on the production of European CG and the methodologies used.
This survey was performed as part of the Eurocancercoms project and supported by funding of the European Union.
Materials and Methods: An electronic questionnaire based on the "Appraisal of Guidelines Research and Evaluation" (AGREE) was developed and sent to the different ECCO members and other Scientific European Organisations involved in cancer care.
Between April 2010 and July 2010, 30 European Cancer Organisations (ECOs) were contacted and 70% responded to the questionnaire. Of these, 38% were not involved in the production of CG.
Results: The majority of the CG were treatment- or disease-management related (84.6%) while 15.4% were on prevention, 15.3% on screening and 46.2% on diagnosis. The objectives were appropriate clinical care (76.9%), cost containment (7.7%) or both (23.1%). Almost all organisations developed CG for their members but more than half were also aimed at policy makers (53.9%).
69% developed CG according to specific instructions or a structured process while 31% mentioned that there were no specific guidelines for guidelines development. The median costs for the development of a CG was 25,000−50,000 euro.
All CG were developed by searches in an electronic data base and in 46.2% there was a manual evaluation of the original articles. Only a minority used unpublished data. Analysis of the evidence as basis for a CG was by systematic reviews (84.6%) while experience-based evidence accounted for 69.2%. The methods used to formulate the CG was by informal expert consensus (53.9%); formal expert consensus during consensus conferences, nominal group technique or Delphi technique (53.9%); an evidence-linked system with a rating scheme (38.5%) or a subjective review (23.1%). CG were reviewed by internal and/or external review (both 69.2%); comparison of CG developed by other groups (61.5%) or clinical validation in a pilot testing or trial implementation period.
Problems identified were the high cost per CG, that only 38% of ECOs gave an expiry date for their CG, that cancer patients were not involved in CG development; and that 69% of ECOs did not provide methodological training for members of the CG development group.
Conclusions: This survey shows that many ECOs are producing CG. Since CG development is both costly and time consuming, a coordinated approach should be encouraged.

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Health-Related Quality of Life in General Sovenian Population Assessed by the European Organisation for Research and Treatment of Cancer Core Quality-of-Life QLQ-C30 Questionaire

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Background: Health related quality of life (HRQOL) has become an important endpoint for cancer patients survivors. The aim of this study was to provide reference values for the EORTC QLQ-C30 in the general Slovenian population and to investigate differences in HRQOL with respect to age, gender and sociodemografic characteristics.
Methods: The EORTC QLQ-C30 questionnaire supplemented by a sociodemographic questionnaire was mailed or distributed to randomly selected individuals in the Slovenian population aged 18−90. The QLQ-C30 standard quality of life dimensions were calculated from answers. Each HRQLQ dimension is presented by mean and standard deviation, the distribution of all socioeconomic features is shown with relative frequencies; age was categorized into seven classes by 10-years groups. The distribution of sociodemografic features in our sample was compared with population data. The differences in HRQLQ (estimated by different dimensions) by sex and age groups was assessed by Student t-test and by ANOVA respectively.
Results: 657 individuals completed the questionnaires. Mean age was 48 ± 1 for the 388 women and 52 ± 14 for 258 men. The sex and age distributions in the sample do not completely correspond to national averages: the share of females is bigger and our individuals are on average two years older. The allocations of individuals to specific social features match the target quite well.
The distribution of all HRQOL variables is expectably skewed as most individuals reported no symptoms and best functioning. In global health status men reported better functioning, the same is true for all HRQLQ subdimensions and for financial problems. The difference was statistically significant for emotional, role and physical function. Correspondingly all symptoms were reported more frequently in women.
Global HRQOL in the sample decreased with increasing age with the main break in the age group 50−59. The same is true for physical function and to certain extent also for cognitive, role and social function. There is no difference in emotional function, symptoms or financial problems among age groups.
Conclusions: These results and some other which can be derived from the same dataset are interesting from clinical point of view: the age- and gender- adjusted HRQOL level of general population norms will facilitate the interpretation of HRQOL data in cancer patients. The preliminary analysis showed that some other social features should not be neglected as well.

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Amount of Cyclophosphamide Excreted in the Urine of Patients During the 48h After Chemotherapy and Secondary Enviromental Contamination of Home Settings Due to the Drug

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Background: Urine, faeces, blood and vomit of cancer patients undergoing chemotherapy contain anti-cancer drugsin the active state, and contact with these substances. The objectives of the present study were to determine the amount of cyclophosphamide that could be excreted in the urine of patients during the 48 hours after chemotherapy with the drug, and to survey the of secondary environmental contamination of homes with the drug caused by excretions of patients.

Material and Methods: The study involved five outpatients with breast cancer. Urine samples were took 5 ml each time they urinated during 48 h after receiving chemotheapy. Wipe surveys were conducted to clarify the status of contamination of cyclophosphamide in the home settings at 48 h after receiving chemotherapy. All samples were stored frozen after sampling and during transport until sample preparation and analysis. Cyclophosphamide was analysed using the GC-MS methods, but on a GC-MSMS system (Exposure Control B.V., The Netherlands).
Results: Cyclophosphamide was detected in all samples. The percentage of the total dose of drug excreted in the urine of the four patients over 48 h ranged from 19.3% to 34.2% and averaged at 24.2%. Environmetal contamination of the drug in the homes of the five patients was detected 17 of the 30 target area. The drug was detected on the toilet seat in the homes of all patients. The degree of contamination was 8.35–0.04 ng/cm^2, and averaged at 3.35 ng/cm^2. The toilet seat was the most contaminated among all the target area. Contamination of 1.53 ng/cm^2 and 0.19 ng/cm^2 was observed on the toilet floor, 0.22 ng/cm^2 on the toilet lid and 0.79 ng/cm^2 on the toilet-door knob.
Conclusion: The present study identified the amount of a drug excreted over time in the urine of outpatinets receiving chemotherapy. It also provided an understanding of secondary environmental contamination of home settings with cyclophosphamide through patient excretions such as urine and faeces. The drug was detected in all urine samples provided by patients during the 48 h after chemotherapy. The degree of drug contamination of the home environmental varied depending on the patients. However, the drug was detected on the toilet seat in the homes of all patients, and this target area showed the highest degree of contamination among all target areas. It is important to prevent contamination with cyclophosphamide in home settings to avoide exposure of family members and friends to these drug.
This study was supported by a grant from The Secom Science and Technology Foundation in 2010.

3630 POSTER

Development of 46 Quality Indicators for Cancer Care in Office-based Medical Oncology

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Background: The aim is to develop a set of quality indicators for office based medical oncology practices. They will be used for an indicator-based quality measurement and peer to peer benchmarking by the WINHO department (collaboration of 210 medical oncology practices in Germany). The indicators should cover all areas of cancer care in office based oncology with a special emphasis is on breast and colorectal cancer. The Quality Oncology Practice Initiative and its indicators are a paradigm for this study.
Material and Methods: Relevant indicators were collected by internet and literature review. The indicator selection was done with a two-step expert rating procedure (modified RAND/UCLA). The indicators were rated concerning (1) importance/relevance, (2) benefit for patients, (3) whether they are within the responsibility of office based oncologists, (4) representation of high quality of care and (5) if the data is already present in patient records. All indicators were rated on five stepped categorial rating scales. Based upon the results of the 1st rating session, the indicators were modified before the 2nd rating. The expert panel consisted of 25 experts from oncology associations, members of the open quality management group of the WINHO department and participants from patient support groups.
Results: A preliminary set of 272 quality indicators was collected by literature review. Due to redundancy and/or low specification level the set was reduced to 67 indicators. In the first rating session, 37 indicators were homogeneously rated as relevant and meaningful for high quality of care in office based oncology. The result of the second session was a set of 46 (32 documentation & therapy, 5 colon, 9 mama) quality indicators. We are currently doing a feasibility test of all 46 indicators. First findings indicate that the data for the construction of 31 out of 46 indicators are already present in patient records.
Conclusions: QOPI indicators are to some extent adoptable for German practices as well. First results of the feasibility test indicate that it will take considerable effort from all involved parties to embed the data collection for a starter set of quality indicators into a daily practices routine. A pilot study about the implementation of the routinely data collection for the indicators has to be done.
This study was sponsored by the German Cancer Aid DKH.

3631 POSTER

Health Technology Assessment of High-intensity Focused Ultrasounds for Prostate Cancer

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Background: HIFU ablation represents a new treatment for prostate cancer management. By an endorectal probe enclosing a piezoelectric or piezoceramic ultrasound transducer, energy is focused to the target tumour without damaging the surrounding tissue.
Objectives: Agenas (the Italian national agency for regional healthcare) carried out an heath technology assessment (HTA) to evaluate effectiveness and safety data from scientific literature on the HIFU treatment of localised prostate cancer compared to standard treatments; to describe the level of adoption and utilisation of the technology in Italy; to perform an economic analysis on the utilisation of the technology within the national health system (NHS).
Methods: We performed a systematic review of evidence. We were interested in studies reporting on effectiveness and safety of the HIFU treatment compared to alternatives in the target population, i.e. males with localised prostate cancer (T1-T2), with low or intermediate risk disease who are being treated with curative intent.
We considered primary as well as secondary literature documents published from 2002 in English or Italian. Primary studies were searched on the major databases (EMBASE, Cochrane Library and Medline). Secondary literature studies were searched on the Cochrane Database of Systematic Review and on the CRD database. A context analysis was carried out by a national survey to describe the level of use and dissemination of the HIFU technology in Italy.
Results: Our study allowed us: to produce a systematic review of evidence on the use of HIFU technology for the treatment of the target population; to produce a comprehensive overview of the distribution and use of the technology within the healthcare providers of the Italian NHS; to assess the costs associated to the HIFU treatment of prostate cancer as compared to standard treatments; to describe the economic and organizational impact of the technology.
As implications for practice and research, our HTA report could be a useful decisional tool at all the levels of the NHS, and highlight the evidence gaps that may be the main targets for the further clinical or economic studies.

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Women Prefer Adjuvant Endocrine Therapy to Chemotherapy for Breast Cancer Treatment

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Background: Previous studies reported that most women with early breast cancer judged a small likelihood of increased survival sufficient to elect adjuvant chemotherapy and endocrine therapy, despite its inconvenience and side effects. We attempted to determine the preferences of women regarding the benefits they considered necessary to make adjuvant therapy worthwhile, and to compare preferences for adjuvant endocrine therapy, chemotherapy, and trastuzumab therapy. We also investigated the effect of information about cost on women's treatment preferences.
Patients and Methods: Consecutive women who had a medical examination at the Breast Clinic, Ota General Hospital, were included in our study. We collected a questionnaire from a total of 365 women; 297 completed responses were included in the study. The survey was a 2-page questionnaire, including sections about a woman's background, treatment, what the woman had been told about options for treatment, and the advantages and disadvantages of adjuvant therapy. We asked the respondent to estimate her prognosis with and without adjuvant therapy, what degree of benefit she felt was acceptable to engage in adjuvant therapy, and what kinds of additional information she felt would be worthwhile to have. Fisher's exact test was used to determine the association of worthwhile and categorical clinical characteristics.
Results: Among 297 women, 105 had breast cancer that had been treated and 192 did not have breast cancer; 38% of women judged that a 5% or less gain in the probability of survival was sufficient to make endocrine therapy worthwhile; 28% participants judged that chemotherapy was worthwhile; and 24% participants judged that trastuzumab therapy was worthwhile. Women indicated that they were more likely to receive adjuvant endocrine therapy than chemotherapy or trastuzumab therapy, for the same gains in the probability of survival. Cost information about treatments