3626 POSTER

Communicating Risk in Familial Cancer: the European Patient Perspective

C. Maddock[1], D. Schrijvers[2], M. Rosselli Del Turco[3], L. Marotti[3]. [1] *Tenovus, Research, Cardiff, United Kingdom;* [2] *European CanCer Organisation, Education, Brussels, Belgium;* [3] *EUSOMA, Education, Firenze, Italy*

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.

3627 POSTER

European Cancer Guidelines: a Survey

D. Schrijvers[1], M. Rosselli Del Turco[2], L. Marotti[2], C. Maddock[3]. [1] *European CanCer Organisation, Education, Brussels, Belgium;* [2] *EUSOMA, Education, Firenze, Italy;* [3] *Tenovus, Research, Cardiff, United Kingdom*

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.

3628 POSTER

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

V. Velenik[1], D. Strbac[1], J. Maucec Zakotnik[2], V. Zadnik[3]. [1] *Institute of Oncology, Radiotherapy, Ljubljana, Slovenia;* [2] *National Institute of Public Health, SVIT Department, Ljubljana, Slovenia;* [3] *Institute of Oncology, Epidemiology, Ljubljana, Slovenia*

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.

3629 POSTER

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

M. Yuki[1], K. Takase[1], T. Ishida[2], S. Sekine[2], A. Miura[1]. [1] *Fukushima Medical University, Shool of Nursing, Fukushima, Japan;* [2] *Fukushima Medical University, Shool of Medicine, Fukushima, Japan*

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.