

understand and require in the way of information about genetic risk (ii) impact of genetic counselling and testing on mental health and (iii) management of breast/ovarian risk cancer.

**Method:** Prospective design; patients are evaluated pre- and post-genetic testing using pre-validated and reliable measures which assess; mental health, cancer worry, perception of risk, reasons for taking a gene test, options for management of cancer risk in carriers, family cancer burden, and health locus of control.

**Results:** This trial is in progress (N = 110). Data from genetic counselling studies indicate that consultands do not recall numeric risk information and remain anxious. A significant number of women having genetic counselling continue to over-estimate their risk. Preliminary results from a cohort undertaking genetic testing by linkage analysis indicate that female gene carriers cope less well if their carrier status results are unanticipated. The uptake rate from this cohort for genetic testing was 41% overall and 59% in females.

**Conclusions:** Uptake rates suggest a high demand once gene testing is widely available. The data indicate that cancer worry remains high in a significant minority of women. Issues highlighted by these data are; (i) the need for guidelines on how best to inform and educate women about genetic risk, (ii) a clearer management strategy for optimising future health in women who are gene carriers, and (ii) need for psychological services for those who suffer adverse consequences of testing.

282

ORAL

### Adjuvant chemotherapy for breast cancer patients: Patients' expectations and physicians attitudes

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**Purpose:** There seems to persist some unclarity about the theoretical and clinical status of adjuvant chemotherapy. Our goal was to shed light on the expectations of patients and the views of physicians about this treatment.

**Methods:** Two matched questionnaires were prepared: one for patients and one for physicians. They dealt with the goals and the probability of their attainment, the side-effects and the difficulty of the treatment. Patients responded to these questions in general and about themselves, and the doctors – about the desirability of imparting information about these issues. The questionnaires were administered to 80 breast cancer patients and 50 doctors in different hospitals.

**Results:** As compared to doctors, patients checked more goals, more extreme probability values and fewer side-effects. Patients tended to consider themselves as close to the typical patient type. Doctors tended to recommend imparting little information, especially those with more experience. Degrees of correspondence between doctors' responses, and between the responses provided by doctors and patients were low.

**Conclusion:** There is need for more consensus about the information given about adjuvant chemotherapy, so that patients' views may become clearer and more focused.

283

ORAL

### Using new technology to disseminate information on breast cancer to women

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The growth of the information society will have far-reaching benefits for the population as a whole. Through the use of information technology, specific information can now be accessed and disseminated in a much more effective manner. The emergence of the Internet as a powerful tool of communication and an increased use of computer technology can be of particular relevance to accessing and disseminating health information to women.

The European Institute of Women's Health developed a cancer information pack on women specific cancers in 1996 by availing of the use of new technology. The pack was designed so that information on prevention, cause and risk factors associated with women specific cancers could be accessed effectively by women through the use of technology. The CanCom project was produced on computer disc so that it could be accessed in any environment – the office, the home or any location with computer facilities. A bottom up approach was used to ensure that the information was packaged in a format that suited the required needs of women in the community.

The advent of new technology offers those concerned with health care a valuable opportunity. The networking of technological systems, the transfer of data, the utilisation of image, sound and text ensures an exploitation of information that transcends cultural differences. The utilisation of technology

to combat breast cancer offers a powerful medium to ensure that the women of Europe avail of accurate, reliable and up to date information.

284

ORAL

### A patient model of effective communication for screening mammography

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**Purpose:** In adherence to breast cancer screening, physician-patient communication has long been perceived as important but is rarely tested in multivariate models. The National Cancer Institute of the National Institutes of Health funded this four year study to develop a physician-patient cohort model of effective communication using a combination of quantitative and qualitative (focus groups) data; the patient model is presented here.

**Methods:** After 65 primary care physicians were recruited from Los Angeles County, 905 of their female patients between ages 50–80 participated in 45 minute bilingual interviews in 1997.

**Results:** The average age of this older sample was 65; 73% were white, 11% black, 12% Hispanic and 4% were Asian. 70% reported adherence with mammography maintenance (2 mammograms within 4 years) but there were notable race/ethnic and income differences. For example, 75% of whites versus 55% of Hispanics reported adherence which is the primary outcome measure of this analysis. Independent measures included several socioeconomic, physician-patient communication and quality of life variables. The final multivariate patient model included three significant predictors of adherence: patient's perceived level of physician enthusiasm for mammography, household income, and race. Physician's enthusiasm was operationalized in focus groups as a combination of physician communication and caring skills. White and black women were almost twice as likely (Odds Ratio = 1.9) as Hispanic and Asian women to be adherent while women whose income was over \$15,000 were over 1 1/2 more likely (OR = 1.7) to be adherent compared to lower income women. Finally, women who perceived their physicians to have a lot of enthusiasm for mammography were 1 1/2 times more likely (OR = 1.5) to be adherent compared to women whose physicians were perceived to have no or some enthusiasm.

**Conclusion:** These findings are encouraging since physician communication skills, unlike other predictors such as patient race and income, can be taught and learned, thus increasing the possibility of improving adherence among older minority and low income women.

285

ORAL

### National survey of women with breast cancer in Australia

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**Purpose:** The National Health and Medical Research Council of Australia released Clinical Guidelines for the Management of Early Breast Cancer in 1995. The Guidelines make recommendations about both clinical care and the information and advice that should be offered to women. For example, the guidelines stress the importance of appropriately informing women of their diagnosis, involving them in decisions about management and providing information about their disease and its treatment. The National Survey was designed to assess the extent to which these recommendations have been adapted.

**Methods:** 600 women diagnosed with early breast cancer between 6 and 12 months previously were asked to take part in telephone survey. The survey instrument had been previously assessed for reliability and validity. Women were identified through the cancer registries to provide a representative national sample.

**Results:** Preliminary results suggest that most women feel they were provided with the opportunity to be involved in decisions about treatment; however, not a aspects of the guidelines were routinely implemented. Results from the full sample will be presented at the meeting.

**Conclusion:** The results will be discussed in terms of strategies for encouraging the adoption of recommendations about supportive care.