of Italian Republic to increase awareness of breast cancer problems. In particular, we presented a petition to Parliament to simplify the procedure related to obtaining free breast prothesis after mastectomy. We obtained that a woman operated can now take possession of the prothesis immediately, independently of civil invalidity, just presenting health record.

In 1997 the efforts of the Italian Forum will concentrate on training programs for breast cancer advocates. A one day course on general aspects of breast cancer (epidemiology, risk factors, ethical committees, etc.) is planned for September. Another course dealing with screening problems is planned for October. The 3rd Conference of the Italian Forum will be held in Bari, October 1998.

291 POSTER

Women prefer breast cancer prognosis expressed as chance of cure to 10-year survival

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Introduction: Fraction of normal remaining life (NRL) is a novel method of expressing survival in terms of cure rates rather than 10 year survival. We investigated how women would like their diagnosis and prognosis to be given, and determined whether the NRL method is preferred.

Methods: A structured questionnaire was administered to 77 women (57 well women (ww) and, after ethical approval, to 12 breast cancer patients (cp)) who had completed active treatment.

Results: Mean age was 45 years for ww (range 22–73) and 58 (45–82) for cp. 94% felt that diagnosis should be given in the clinic (vs. 6% over the phone) and given by the consultant (ww 70%; cp 83%), the registrar (ww 16%, cp 17%), family physician (ww 40%, cp 0%), breast care nurse (ww 44%, cp 0%). At the time of counselling, 26% of ww and 64% of cp would prefer to be alone; accompanied by their spouse (61% ww and 27% cp); a friend/other family member (47% ww and 9% cp). Out of 12 cancer patients, 7 had not been given their prognosis, 3 were given it in terms of very-good/good/not-so-good and 2 in terms of 10 year survivals. The vast majority of women wished to know their prognosis and preferred it in terms of cure rates (chance of living their full NRL) in addition to a subjective description (table, NB: options not mutually exclusive).

Preferred way of communication of prognosis Well Women Breast Cancer Patients

No prognosis 2/57 (4%) 1/12 (8%)

Descriptive (very good, good or not so good) 36/57 (63%) 5/12 (42%)

10 year survival 29/57 (29%) 1/12 (8%)

Cure rates (full NRL survival) 41/57 (72%) 10/12 (83%)

Living full normal life span (full NRL) was interpreted as cure by 85% (46/53) of well women and 100% (12/12) breast cancer patients. Living at least 80% of NRL was acceptable for cure, to 68% of women.

Conclusion: Women prefer their prognosis in definite terms along with a subjective description. Communication of prognosis in terms of NRL is meaningful, and women accepted living full NRL as cure. It is evident from this study that leaving patients in the dark is no longer the humane option.

292 POSTER

Endocrine therapy in breast cancer: A nurse education package

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A need has been identified for educational materials which help in teaching nurses about endocrine therapy and its role in the management of breast cancer. The aim of supplying such educational materials is to help nurses work with their medical colleagues to educate their patients and provide much valued psychological support to women with breast cancer. *The Working Group on Living with Breast Cancer,* sponsored through an educational grant from Zeneca Pharmaceuticals, has set about developing a *Nurse Education Package* for use throughout Europe. The *Working Group* is a multidisciplinary team comprising of oncologists, radiotherapists, psychologists and nurses dedicated to the management and treatment of breast cancer.

The *Nurse Education Package* includes expert-reviewed information on the biology and physiology of the breast, breast cancer and the pharmacology, rationale, and use of endocrine therapy. It also contains information on clinical trials to date involving endocrine therapy, providing valuable insights into the evolving nature of endocrine therapy, thus enabling nurses to answer many of their patients' questions. Furthermore, a crucial component of the *Nurse Education Package* is information on the management of side-effects, since good 'quality-of-life' is such a major goal when working with women with breast cancer.

Since the structure of nurse education varies among countries, the guide is produced as a 'core' resource manual which can be easily adapted and translated at a local level. The *Nurse Education Package,* which will be presented for the first time at this meeting, is an important tool in helping to meet the training needs of nurses involved in the care and treatment of women with breast cancer. We hope it will increase the level of understanding of endocrine therapy among nurses and empower them to confidently explain treatment options to their patients.

293 POSTER

Bottle-necks in Dutch breast cancer care

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Purpose: Dutch breast cancer patients are in a privileged position. Even so improvements in breast cancer care are possible and necessary. The Dutch Initiative Group of Europa Donna has held a survey among doctors and nurses and among breast cancer patients. The purpose is to build the agenda of a future Europa Donna Forum.

Methods: A questionaire was send to doctors and nurses concerned with breast cancer care and to active members of the Dutch breast cancer patient organisation (LCBB). Three main points of concern in breast cancer care were asked.

Results: The "top-5" points of concern are:

Doctors (n = 182)
(a) restriction of breast cancer screening over 70 year
(b) absence of national guidelines for diagnose, treatment, follow-up
(c) treatment delay
(d) insufficient interdisciplinary communication and care
(e) insufficient multidisciplinary treatment

Nurses (n = 78)
(a) insufficient communication between health professionals
(b) restricted possibilities of psycho-social support
(c) women's lack of knowledge of early diagnostics
(d) insufficient patient information
(e) shortage of oncology-nurses

Patients (n = 55)
(a) insufficient patient information
(b) insufficient communication between professionals
(c) restricted possibilities of psycho-social support
(d) restriction of breast cancer screening under 50 year
(e) treatment delay

Conclusion: Many points of concern in breastcancer care are observed by doctors, nurses and patients. Pressure points will be selected to build the agenda of a Dutch Europa Donna Forum.

294 POSTER

Nurses' role in breast cancer control in a multinational community

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Breast cancer is the most common malignancy affecting women in Europe and the U.S. today. Oncology nurses have been involved in various aspects of cancer control, education, treatment, rehabilitation and advocacy. Nurses today face the added challenge of providing care in communities with culturally diverse populations. An interdisciplinary and multinational task force was convened to develop a program of culturally competent and comprehensive breast cancer care to meet the needs of a multinational community in Naples, Italy.

We examined existing cancer services available in both the medical military community and Italian host community and identified 5 areas of opportunity to improve breast cancer services. Concurrently, we identified those cultural issues which influence the perspectives of breast cancer for the patients and health care providers, and that influence the relationship between provider and patient. Drawing on local, national, and international resources we developed 1) clinical pathways for breast cancer management, 2) transcultural nursing education program for Italian and U.S. health care institutions, 3) multicultural/multilingual breast cancer education and support group, 4) culturally, sensitive public education program, 5) partnership among breast cancer advocacy groups. The process of needs assessment, program development, implementation and evaluation are discussed. Several areas for research are identified including patient satisfaction and quality of care, perception of adequacy of care, outcomes of treatment, and nurse satisfaction. The role of the oncology nurse specialist as program coordinator is reviewed.

295 POSTER

The Canadian Breast Cancer Initiative

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In December 1992, the Canadian federal government launched the Canadian Breast Cancer Initiative (CBCI) with funding of $25 million over five years, to build partnerships and networks to enhance research, prevention, care and treatment, professional education and information exchange on breast cancer. The CBCI was based on the strengthening of existing partnerships, the development of new alliances and the involvement of consumers (breast cancer survivors) throughout the process. A second phase of the CBCI was announced by the Canadian federal government in April 1998, with funding totalling $35 million over the next 5 years. The CBCI Phase II represents a balanced expansion of research and programs, building on the products, services and outcomes of CBCI Phase I, while incorporating the capacity to address new knowledge gaps and emerging issues related to breast cancer. It places emphasis on: increasing knowledge; dissemination and/or implementation of the lessons learned and products developed under the CBCI Phase I; strategies to increase the percentage and range of women participating in organized screening; dissemination of information to increase professional and public awareness; developing linkages across all activities of the CBCI Phase II; and, strengthened, independent evaluation of key products, services and activities to provide evidence of the most viable and effective strategies to address breast cancer issues. This presentation will discuss who is involved in the partnership, the major accomplishments to date, the activities underway and the policy implications for Canada.

296 POSTER

Breast cancer: The nurse's role in genetic counselling

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Although most people working in the field of medicine are familiar with the term genetic counselling, it is extremely rare to read a proper definition. The authors support the following definition: *genetic counselling is the process by which patients or relatives at risk of a disorder that may be hereditary, are advised of consequences of the disorder, the probability of developing and transmitting it and the ways in which this may be prevented or ameliorated:* (P:S: Harper, "Practical Genetic Counselling"). At least three major aspect are essential in genetic counselling: 1. The diagnostic aspect; 2. The actual estimation of the risk; 3. The supportive role of the nurse, in order to ensure that patients and their relatives will actually benefit from advice and preventive measures available. The National Cancer Institute of Milan promoted a survey to evaluate the chances of developing an hereditary cancer. 486 questionnaire were handed to women admitted for breast cancer. 456 (93.8%) were considered valid (no tumor or benign tumor were found in 80 Patients). Of the remaining 376 cases of malignant epithelial tumors 20.4% had a family risk. Sattin (1985) showed that at all ages first degree relatives of women with breast cancer had a 50% higher risk of developing the disease than other groups. When a family with an hereditary predisposition to breast cancer is identified, it is important to draw an accurate pedigree and inform women of the risks and the available choices. McGuire (1979) Albano and Lynch (1981) suggested that when specialized nurses are involved in the collection of family history, women appear to be more at ease and less defensive. The role of specialized nurses includes facilitating women to make informed decisions regarding treatment and helping them to cope with the uncertainty of the situation.

297 POSTER

Knowledge and beliefs about breast cancer prevention in an unselected female Italian population

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Purpose: We conduced a self administrered questionnaire to explore women's knowledge and beliefs about breast cancer prevention modalities.

Methods: We distributed this questionnaire to women entering several hospital units in Italy.

Results: Up to now we have collected 3715 questionnaires. In the sample 79.6% of women aged from 20 to 59 years, 78% had a medium-high educational level, 35.4% were housewives, 26.3% were smokers, 44.3% drank wine and 46.5% had almost one relative affected by a neoplastic disese. The information about prevention modalies was assessed as good in 36.7% questionnaires but the prevention was really prevention was really performed in a low percentage: 67.3% of the women knew about breast self-examination, 47.3% performed it but only 22.8% did it monthly; 49% of the women underwent a specialist visit once a year. In the last five years 31.9% of the women never underwent mammography. The main obstacle in performing breast cancer prevention exalinations was shows out of indolence by 34.4%, out of fear by 24.5%, for economic motives by 14.5% and and for lack of quick benefit by 3.8%. About 59% of the women thinks that the health authorities advertises the prevention too little and 81.5% that the main part of cancer prevention education should be carried out by health authorities (27.4% by school).

Conclusions: More enterprise is needed on the part of health authorities to improve cancer prevention.

298 POSTER

Patients' perceptions of routine follow-up after treatment for breast cancer and nurse-led clinics

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Purpose: To ascertain patients' perceptions of medical routine follow-up after completion of treatment for breast cancer with a view to designing an alternative model for follow-up care.

Methods: Data of patients' views were collected using semi-structured taped interviews from a systematic stratified sample of patients attending medical follow-up clinics. These perceptions were inductively analysed and coded to ascertain predominant themes.

Results: A large proportion of the patients felt that the examinations were hurried and poor continuity was deemed unacceptable by 92% of the participants. The majority of patients felt uncomfortable expressing emotional concerns or asking questions. Three quarters of the sample stated that they would prefer to receive all or part of their follow-up from a breast care nurse.

Conclusion: Existing practice should be modified in light of resource implications and cost efficiency. On the basis of these results a prospective randomised trial has commenced to compare a nurse-led intervention with conventional medical follow-up for patients with breast cancer.

299 POSTER

Promoting healthy women

M. Lewis, S. DiMaria. *Breast and Endocrine, Surgical Oncology Unit, Royal Adelaide Hospital Cancer Centre, Adelaide, Australia*

The Women's Health Centre at the Royal Adelaide Hospital was opened in 1994 in recognition of the benefits of bringing together, under one roof, medical specialists and health care workers who deal with aspects of health care which are specific to women. The personal nature of many conditions experienced by women often means that the busy outpatient clinic in a large public teaching hospital is not an appropriate place in which to address these problems. In addition, the women's health services were fragmented within the hospital often requiring more than one visit for tests to be performed.

Housed in a refurbished heritage building, providing direct access onto a main thoroughfare, close to the city, the Women's Health Centre is on the periphery of the hospital campus without having to enter the main hospital building. This allows women access to advice, discussion, medical consultation, investigations and treatment, in one visit. Services include assessment of breast disorders, breast and gynaecological oncology, breast cancer