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 manage-