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Caring About Women and Cancer (CAWAC): The perceptions, experiences and evaluation of cancer care among European women

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Purpose: The CAWAC program is a unique pan-European effort dedicated to supporting female cancer patients and their carers throughout 16 countries. The first initiative of the program was the first ever European survey to assess the experiences and views of women with breast and gynaecological cancer.

Method of Patient Survey: For the recruitment of hospitals and patients, a two stage sampling process was employed. In Stage I, hospitals were selected by stratified random or purposive sampling to ensure broad representation in each country by region and in some countries by hospital type. In Stage II, clinical staff distributed questionnaires, according to selection criteria, to out-patients visiting or in-patients hospitalized who were willing to participate, within a minimum period of 30 days. To correct for disproportionate representation, data were weighted by national and regional population distribution and by hospital size and type.

Preliminary Results: To date a total of 13,139 questionnaires from 16 countries have been processed. The preliminary distribution of tumors was breast (78%), ovarian (10%), cervical (4%), uterus (3%) and vulval (1%). The mean age was 55 yrs. In-and out-patients represented 14% and 81% of all respondents respectively. The index of well-being was high: 72.

Conclusion: The high response seen in this pioneering study demonstrates in the first instance the strong desire of women throughout Europe and Israel to express their views on their care. Further analysis of these responses is continuing towards a conclusive outcome of the research leading to indicators for change.

Funding for the program and awareness is provided by Bristol-Myers Squibb – committed to building understanding and improving the status of care of female cancer patients in Europe. Scientific advice and assistance is offered as a voluntary contribution to the program by members of the European Core Advisory Board (ECAB) and National Advisory Boards (NABs).

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How can survival for women in Scotland with breast cancer be improved?

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Purpose: We studied changing patters of care and outcome for women undergoing surgery for breast cancer in Scotland to identify ways of improving care.

Methods: In this retrospective study clinical characteristics, surgical and non-surgical treatment and service factors (surgical case load, deprivation and geographical area) were recorded from all women undergoing surgery for breast cancer in Scotland during 1987 and 1993.

Results: There was sufficient follow-up to evaluate survival in the 1987 cohort of women. In a multivariate analysis the region of Scotland where the woman was treated affected survival ($P = 0.02$); women in areas with greater use of adjuvant systemic treatment generally had better survival. There was also a trend for women entering clinical trials to have better survival ($P = 0.1$). Between 1987 and 1993 there was an increase in the number of women undergoing surgery (from 1619 to 2069) and in the use of adjuvant radiotherapy (from 638 to 1,137). There was a 41% increase in the number of women receiving adjuvant endocrine therapy and a 214% increase in those receiving adjuvant chemotherapy but only a 16% increase in the number of senior non-surgical oncologists. Over this period women referred to an oncologist were significantly more likely to receive adjuvant systemic therapy and to enter clinical trials ($P < 0.05$).

Conclusions: This population-based study suggests that the increasing use of adjuvant systemic therapy will enhance survival for women with breast cancer. Reducing geographical vaariations in treatment, increased participation in clinical trials and improved patterns of referral should also contribute to better outcomes. These service improvements will require investment in resources.

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Breast self examination proficiency in older Black and White women: Efficacy of video self instruction

R.Y. Wood. *Boston College, School of Nursing, Chestnut Hill, Massachusetts, USA*

Purpose: Older women do not follow recommended screening procedures despite age increases in breast cancer incidence and mortality. This study assessed the use of innovative ethnically sensitive self-monitored video breast health kits to foster breast self examination among older African-American and Caucasian women.

Methods: A pretest-posttest design was used with a volunteer sample of 62 women 60–79 years of age. Subjects were their own controls. Data obtained in two one hour interviews explored disability covariates of aging. Instruments included the Breast Self-Examination Proficiency Rating Instrument (BSEPRI) and the National Health & Epidemiological Follow-Up Survey (NHEFS-revised). Subjects were pretested on BSE proficiency and lump detection using a 5-lump vested breast model custom-designed to approximate the look and feel of older breasts. All subjects used breast health kits for thirty days at home and then were posttested on the variables.

Results: Mean posttest skill scores were significantly higher than pretest skill scores ($t = 7.32$, $p < .0001$) and mean posttest lump detection scores were significantly higher than lump detection pretest scores ($t = 4.23$, $p < .0001$) with reliability coefficients in the .80 range. Comorbid variables of arthritis, swollen finger joints, limited finger range of motion and pain on movement, cataracts, and wearing corrective lenses did not influence BSE proficiency. Ethnic differences were tested with ANCOVA. African-Americans had significantly better BSE skills than Caucasians ($F < 001$) but similar lump detection scores. Data were used to produce age and ethnic-sensitive breast health kit prototypes. Preliminary results of testing with 600 low-income women in the Northeast and Southeast US will be presented.

Funding: National Cancer Institute (SBIR Phase II) 2 R44 CA 63935–02. Dr. Wood is President of HealthWood, Inc., which markets video kits in the US.

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"BSE RAP": The evaluation of a breast self-examination music program, developed to create breast health awareness among teens and their families

Johanna Lombardo Ehmann. *Johanna's Cancer Rehabilitation Nurse Consultants, Albany, N.Y., USA*

Purpose: "BSE RAP," a lively breast self-examination music program using a training video and other educational materials, was presented to 170 seventh and eight grade female students.

Methods: Pre- and post-program surveys evaluated students, knowledge and practice of BSE, and their motivation to perform BSE, share materials, and discuss mammography with their mothers and grandmothers.

Results: Pre-program surveys showed 312% of students knew how to do BSE; 7.1% performed BSE, and 14.1% knew if their mothers/grandmothers had mammograms. Post-program surveys showed 61.2% of students knew how to do BSE; 52A% wanted to practise BSE, and 65.3% would encourage their mothers/grandmothers to get mammograms. More than 130 students surveyed completed a one-month follow-up survey which showed 41.7% had practised BSE; 54.7% shared materials and 33.6% discussed mammograms with their mothers/grandmothers.

Conclusion: The "BSE RAP" music program is an innovative public education strategy which increases teens' knowledge and awareness of BSE and helps disseminate information to their mothers and grandmothers. Oncology nurses use the program to create a positive message about breast health awareness and promote intergenerational ties to save lives.

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Europa Donna in Italy: Activities and goals

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The Italian Forum of Europa Donna was set up in December 1996 after hard groundwork. It currently consists of more than 90 associations dealing with breast cancer spread throughout Italy and of more than 50 women bringing their voice to our organization.

Among a series of initiatives – scientific conferences for lay people, meetings with the associations, press conferences, the representatives of the italian Forum participated to successful meetings with the women Senators 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.

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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.

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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.

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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-