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

S. von Kleist¹. CAWAC European, and Chairs & Co-chairs of National, Advisory Boards; ¹ University of Freiburg, Institute of Immunobiology, Freiburg, Germany

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?

J.C. Twelves, J. Dewar, C. Thomson, A. Gould. Beatson Oncology Centre, Western Infirmary, Medical Oncology, Dumbarton Road, Glasgow G11 6NT, UK

Purpose: We studied changing patterns 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 variations 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; 52.4% 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

Francesca Merzagora. President of the Italian Forum; Forum Italiano di Europa Donna, Vile Beatrice D'este, 37 20122, Milano, Italy

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