4 pts (14%) received bisphosphonates and 2 (7%) - steroids. 12 pts (41%) remain progression free and 17 (59%) have developed disease progression at 6-84 months (median 39 months). 4 pts (14%) died of disease after 60-71 months since dissemination and 25 (86%) are alive after 60-194 months (median 71), of whom 20 (69%) without progression.

Conclusion: There are no clearly identifiable clinical characteristics heralding long-term survival in MBC. The common use of hormonal therapy in long-term survivors may reflect less aggressive tumor behavior, a typical indication for this modality.

Wednesday, 20 March 2002 16:30–18:00

PROFFERED PAPERS

Psychosocial oncology – information – communication – education

141 ORAL

Consumer led patient information: a consensus study

T. Stevens, N. Ahmed, N. Mitchell, D. Wilde, S.H. Ahmedzai. *University of Sheffield, Academic Palliative Medicine Unit, Sheffield, United Kingdom*

Objectives: Traditionally, patient information has been designed by professionals. As part of an intervention study looking at the impact of research information given to patients prior to diagnosis, a novel approach to information design was taken by including consumers at the design stage. This consensus approach has not been previously investigated. The aims were to:

– develop a new process of generating patient information

– utilise this technique to develop consumer information for use in an intervention study

– develop a model of information design that can be employed in future research

Design: A three round consensus approach was used:

– consumer groups reviewed a basic outline of the proposed information

– professionals were asked to refine the information document

– consumer groups reviewed the revised information

Setting: Northern England.

Participants: Five breast cancer support groups, Sheffield Cancer Services Users Advisory Group, primary and secondary healthcare professionals.

Main Outcome Measures:

– to produce patient information using a consensus approach

– to evaluate consumers' and professionals' attitudes toward the process

– to foster links between healthcare profesionals and consumers

Results: The final information document has been produced.

Conclusions: The methodology used was a sensitive, inclusive and focused way of developing patient information. Patients' needs were directly addressed because the study utilised an ethical, bottom up methodology; patients' opinions were considered from the outset and the principle of informed consent was underlined

142 ORAL

Europa Donna model in a developing country with limited resources

G. Nabbout[1], A. Taysoun[2], R. Hamati[2], M. Douaihy[2]. [1] *Department of Surgery, Centre Hospitalier du Nord, Lebanon;* [2] *Volunteer worker*

Background and Objectives: The main cancer-related problems in Lebanon, as in most developing countries are the lack of public awareness about cancer in general and breast cancer in particular, and the absence of national screening programs and guidelines.

We aimed at creating a hospital-based organization of volunteer local women, working alongside specialist doctors, and non-governmental organizations, with the following objectives:

(1) promote public awareness on breast cancer.
(2) attend to the physical and psychological needs of women with breast cancer.
(3) ensure that patients fully understands their treatment strategies and options.
(4) undertake population based studies and researches with the help of professional staff and local non-governmental organizations.

Work Done: The knowledge and misconceptions in our society were first assessed (presented at the EBCC2), and we published a booklet in Arabic to rectify these misconceptions.

A hospital-based organization of volunteer women was created, and this is a first of its kind in Lebanon. A patient support group prepared, working with women with breast cancer in the radiotherapy and chemotherapy units at the hospital, as well as with local NGO's in different areas.

We have started a campaign for breast awareness and early detection, including lectures, reading materials and a walk-in free breast clinic in the different areas in our region. A free breast clinic was started in May 2001 at the hospital.

A survey among breast cancer patients to assess doctor-patient relationship and the problems encountered by the patients is currently in progress.

We have additional problems to answer to, because of our economic crisis, and more and more patients can't afford the cost of rehabilitation.

We have also started a fund raising campaign to be able to support needy patients and to provide free accessories such as breast prosthesis and wigs for patients.

Comments: With the help of volunteer women and professional staff we are trying to promote breast cancer awareness, help in early diagnosis and improve the quality of life of women with breast cancer in all aspects. Our services are free to all and our funding is through membership fees and contributions.

143 ORAL

Breast cancer management- a general practice (GP) perspective

S. Galetakis[1], C.J. Scott[1], J. Samers[1], R. Drummond[2], S. Neil[5], S. Woolf[3], L. Waters[4]. [1] *Inner & Eastern Melbourne BreastCare Consortium, William Buckland Radiotherapy Centre, The Alfred;* [2] *Inner & Eastern Melbourne BreastCare Consortium, Peter MacCallum Cancer Institute, Victoria, Australia;* [3] *Inner & Eastern BreastCare Consortium, SouthCity GP Services, Victoria, Australia;* [4] *Breast Cancer Network Australia, Victoria, Australia;* [5] *Inner & Eastern Melbourne BreastCare Consortium, Breast Unit @ Mercy Private, Victoria, Australia*

This study conducted by the IEMBCC aimed to assess and describe GPs experience with specialist breast services and to identify GPs education requirements regarding breast cancer.

A 26-item questionnaire was developed and randomly distributed to 450 GPs in the consortiums catchment area. A 23% response rate provided the following information:

On average, GPs had one patient in their practice newly diagnosed with breast cancer per year

GPs referral of patients with breast symptoms was most likely to be made to a private specialist breast service (45%) followed by a public specialist breast service (16%) and this decision was largely influenced by previous experience with the service

GPs communication with specialist breast services was generally described as satisfactory in the initial stages of diagnosis and treatment, however 41% indicated that a phone conversation with a specialist clinician upon patients' discharge from hospital would improve the continuity of patient care

Recent advances in breast cancer management was identified by 65% of GPs as an area which they required further professional development

A resource directory listing available breast services in local areas was requested by 92% of GPs

Results were reported to multi-disciplinary team members of 4 specialist breast services (both public and private) in the consortium.

Three education seminars were conducted in response to the questionnaire findings. Specialist clinicians (surgeons, medical and radiation oncologists and breast care nurses) presented GPs with an overview of the recent advances made in breast cancer treatment and management. An information kit was provided to GPs attending the seminars which included best practice guidelines for the management of breast cancer and a local resource directory.

An evaluation of the seminars indicated that GPs not only furthered their clinical knowledge, but also gained an understanding of the many services available to women and their families such as the breast care nurse service, genetic counselling clinics and lymphoedema services. GPs also indicated that following the seminar they were better equipped and more confident in meeting patients' needs during the treatment phase and beyond.

144 ORAL

Women with early stage breast cancer vs. consulting surgeon's perception on treatment decision-making: Do they correspond?

I. Schou[3], Ø. Ekeberg[2], C.M. Ruland[3], R. Káresen[1]. *[1] Department of General Surgery; [2] Department of Acute Medicine, Ulleval University Hospital, Oslo, Institute of Nursing Science; [3] University of Oslo, Norway*

Introduction: The purpose of the study was to assess if women's perception of receiving a choice between breast-conserving surgery (BCS) and mastectomy (MAS) matches surgeon's perception of giving a choice, and to assess if factors influencing the women choice of surgery are the same as the factors influencing the surgeon's recommendation.

Method: A total of 187 women with early stage breast cancer and 25 surgeons completed questionnaires on influential factor regarding decision making for the women and surgeons and demographics for the women.

Results: Mean age for the women was 57 years. The surgeons considered that it was medically appropriate to give 81% of the women a choice, but gave a choice in only 62%. 59% of the women perceived that they received a choice between BCS and MAS (rs = 0.23, p = 0.001). There were complete agreement between the women's assessment of receiving a choice and the surgeons of giving a choice in 38% of the cases. The surgeons gave their recommendation for surgery in 74%, and 91% of women followed this advice. The main reason for going against the surgeon's recommendation was fear of cancer recurrence by women choosing MAS. Of the patients who were not given a recommendation, 66% chose BCS. The most influential factors for the women's choice were: the surgeon's recommendation (70%), fear of cancer recurrence (89%) and necessity of further treatment (72%). Medical assessment (97%) and the breast appearance in relationship to surgical outcome (82%) were the most influential factors for the surgeon's recommendation. Female surgeons put more emphasis on their assessment of the women's need for security, while male surgeons put more emphasis on the significance of the breast for femininity.

Conclusion: Even when it was medically appropriate to give a choice between BCS and MAS, not all surgeons gave a choice. The women primarily base their choice on fear of cancer recurrence, necessity of further treatment and recommendation from the surgeon. Women, who were not given a specific recommendation, tend to choose BCS. Factors influencing the women choice of surgery are not the same as the factors influencing the surgeon's recommendation. The surgeon's gender was found to influence recommendation for surgery type.

145 ORAL

Ambulatory breast cancer surgery: is it acceptable from the patients' perspective?

M.H. Hebly, C.N.A. Frotscher, M.F. von Meyenfeldt, M.H.A. Bemelmans, G.H. Sie, W.A.J.J.H. Haagh, G.L. Beets. *[1] University Hospital of Maastricht, Surgery, Maastricht, The Netherlands*

Introduction: Minor surgical procedures are often performed in an ambulatory setting. For breast cancer surgery however, day care surgery is generally considered unacceptable from the patients' perspective because of the more complex psychological, emotional and organisational issues. The aim of the study is to identify the barriers and pitfalls of ambulatory breast cancer surgery from the patients' perspective.

Material and Methods: In a pilot study starting in January 2001 breast cancer surgery was increasingly performed in an ambulatory setting. The whole process of diagnosis, preoperative work-up, information and counseling, surgical treatment and postoperative care was continuously monitored. Problems were identified and the procedures adjusted when necessary.

Results: In the first six months of 2001, 70 patients with breast cancer were planned as a day care procedure, 56 went home the day of operation. The most common pitfalls that is leading to patient dissatisfaction or an unplanned admission were: 1) lack of patient information and counseling, 2) health care professionals who are biased against ambulatory breast cancer surgery and who project their concerns, fears and prejudices on the patient and 3) problems with drain care management. The most important adjustments in the procedures were: 1) development of a special patient education and counseling program for patients and their partners by a breast care nurse, 2) better information and cooperation between all the health care professionals involved in ambulatory breast surgery and 3) arrangements for visits at home by a district nurse, starting at the evening of the operation when required. With these measures, we experienced that patients are more satisfied and often eager to go home the same day. The personal attention of the counseling program is appreciated by the patients and partners. The partners now feel involved with the treatment process. The initial prejudice of health care workers against ambulatory breast cancer surgery was replaced by a moderate enthusiasm.

Conclusion: To make ambulatory breast cancer surgery acceptable from the patients' perspective, it needs to be incorporated in a complete program of preoperative education and counseling and postoperative care. Special attention is also required to educate and motivate all health care workers involved. The final conditions for ambulatory surgery will be defined in ongoing quantitative and qualitative research.

146 ORAL

Patient-focused and nurse-led follow-up after treatment for breast cancer

E. Pennery. *Royal Marsden Hospital, Breast Unit, London, United Kingdom*

This study aims to identify the individual needs of women receiving follow-up after treatment for breast cancer and to compare the relative efficacy of nurse-led versus conventional medical care in relation to meeting those needs.

A cross-sectional pilot survey of a stratified systematic sample of patients involved semi-structured, taped interviews and subsequent analysis to reveal predominant themes. These indicated that follow-up examinations were hurried, investigations were not reassuring, lack of continuity was unacceptably poor and most women felt uncomfortable expressing emotional concerns or asking questions.

Much of the research examining current systems of follow-up care cast doubt on the effectiveness of the medical model and the use of routine investigations. Meaningful care depends on the recognition of patients' needs and development of cost-effective, patient-focused interventions. Patients have multiple ongoing psychosocial and physical needs after treatment, yet follow-up in a busy outpatient clinic does not provide the opportunity for comprehensive care and support.

The randomised, prospective study compares nurse-led with conventional medical follow-up. Data was collected using two self-administered questionnaires, Functional Assessment of Cancer Therapy (FACTB) and Your Views of Follow-up Care (in-house).

The end points include an analysis of the relative benefits to quality of life and patient satisfaction resulting from nurse-led or medical follow-up and a comparative cost analysis of the two approaches.

This study has enabled evidence-based discovery of the differences between what doctors and nurses offer and identification of the best professional to enhance future follow-up care. Thus services and resources can be targeted more effectively to meeting patients' ongoing needs. Practice changes can attend to the individual woman's agenda and the issues that they believe hinder the quality of survivorship after treatment for breast cancer (such as management of treatment induced menopausal symptoms). Central to an alternative approach is the transfer of emphasis away from a costly, medically orientated cancer surveillance model, which has questionable efficacy, to a more patient centred, supportive and humanistic model or care.

147 POSTER

ARC breast cancer partners programme - a psycho-educative programme for men

U.M. Courtney. *[1] ARC Cancer Support Centre, ARC Cancer Support Centre, Dublin, Ireland*

The ARC Breast Cancer Partners Programme combines educational and emotional support for men whose female partners have been diagnosed with breast cancer. In 1998 a national omnibus survey of Irish men was commissioned in relation to their attitudes about breast cancer.The results of this survey identified the educational and emotional support needs of men whose partners have breast cancer.

Following a diagnosis of breast cancer, open communication is beneficial when both partners have similar needs for information.However differing needs for information may lead to frustration, rejection and withdrawl by either partner.

Following surgery and systemic breast cancer treatment a woman may experience sexual difficulties related to anxieties about body image compounded by a sense of personal failure.Information and education may help a woman to understand the changes occurring in her body. Similarly, adequate and factual education may help her partner to understand the sequallae of breast cancer and to feel supported and less isolated. It is important that educational interventions be developed and systematically applied so that all affected by a cnacer diagnosis may experience optimal physicla and psychological healing.

The ARC Breast Cancer Partners Programme invites male partners of women with breast cancer to join an educational class while at the same time allowing them an opportunity to meet with other men in a similar situation. The programme is divided into four main areas dealing with the facts and myths surrounding breast cancer, as well as the physical, psychological and socila aspects of breast cancer.

To date over fifty men have taken part in the ARC Breast Cancer Partners Programmes. Thsi paper describes the outcome and perceived benefits of a psycho-educative support programmes for Irish male partners of women with breast cancer. The limitations of the study are discussed as well as the potential for further research in the area of family and partner support following a cancer diagnosis.

148 POSTER

Decision making about genetic testing in hispanic women at familial risk for breast and ovarian cancer

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Commercially available genetic tests can now reveal the carrier status of two of the breast-ovarian cancer susceptibility genes thus far identified-BRCA1 & BRCA2. Although some research has been done regarding decision-making in genetic testing, studies are scant and concentrate mostly on White Anglo females, thus, very little is known about Hispanic and other minority women. This study examined interest in and decision-making about genetic testing in Hispanic women at familial risk for breast and ovarian cancer (Br/OvCa). This study was designed to explore the hypothesis that the decision to undergo genetic testing for Br/OvCa is explained by variations in how Hispanic women perceive the benefits and drawbacks of undergoing testing and their risk of developing cancer.

One hundred and ten Hispanic female first (n=66) and second degree (n=44) relatives of Br/OvCa patients completed questionnaires assessing socio-demographic information, family history of Br/OvCa (used to calculate empiric genetic risk), perceived Br/OvCa risk, interest in and readiness to undergo genetic testing, and perceived benefits (pros) and drawbacks (cons) of testing (used to calculate decisional balance). Eighty percent of the women chose to complete the questionnaires in Spanish, while the rest completed them in English. Ninety-three percent of the sample reported interest in undergoing genetic testing (4% unsure, 4% not interested). Sixty-two percent of participants wanted to pursue testing as soon as possible, 27% in the near future, and 11% not in the near future. Consistent with expectations and prior research findings in the majority culture, the more benefits respondents saw in finding out whether or not they were BRCA1/2 mutation carriers, the more likely they were to show interest in being tested for genetic susceptibility and the sooner they wanted to get tested. Moreover, those who chose to get tested had a significantly higher decisional balance score (pros > cons) than those who were unsure and those who declined getting tested altogether. Likewise, a more positive decisional balance score (pros>cons) also resulted in a desire to undergo genetic testing more rapidly. Similarly, as predicted and in agreement with previous studies, the proportion of women choosing to get tested for Br/Ov Ca susceptibility was significantly higher among those who considered themselves to be at higher risk for developing these diseases than among those who underestimated their lifetime risk

149 POSTER

Factors correlated with fatigue in breast cancer patients

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Fatigue is one of the most frequent symptoms in cancer patients. It is a complex and multi-factorial disorder with physical and psychological dimensions that has been associated with poor quality of life in cancer patients. However, the causes of fatigue are still unknown and this makes it difficult to comment on the problem precisely. This study was designed to investigate the factors correlated with fatigue in Iranian breast cancer patients using Cancer Fatigue Scale (CFS) in addition to a questionnaire containing items on demographic and clinical data, religious beliefs, social support and anxiety and depression. The CFS measures total fatigue score ranging from 0 (lowest level) to 60 (highest level) and contains three sub-scales namely: physical, affective and cognitive fatigue. The questionnaire was administered to a consecutive sample of breast cancer patients attending the Iranian Center for Breast Cancer either for their treatment or follow-up. Univariate and multivariate analysis was performed on data. In all, 112 patients were studied. The mean age of the respondents was 45.7 years (SD = 11.0), mostly had stage II tumors (67%) and had completed their initial treatment (45%). The mean total fatigue score of the patients was 18.7 (SD = 13.5). The regression analysis revealed that fatigue was significantly correlated with depression ($P < 0.0001$), pain

($P = 0.01$), religious beliefs ($P = 0.004$), and dyspnea ($P = 0.02$). However, there was no significant correlation between treatment modalities and fatigue. The study findings suggest that physical and psychological problems in comparison to the cancer treatment (chemotherapy, radiotherapy, ...) have more important role in cancer related fatigue and that it should be recognized and managed even before the commencing cancer treatment.

150 POSTER

Genetic counceling for hereditary breast and ovarian cancer. Our experience at the institute of oncology in Ljubljana, Slovenija

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Purpose: Approximately 5-7% of breast and ovarian cancer patients carry a germline mutation in the BRCA1 and/or BRCA2 genes. Carriers of BRCA1 and/or BRCA2 mutations can be detected by genetic testing. It is known that, in certain ethnic groups, only a few and typical mutations could be detected.

The first purpose of this study was to assess the compliance of women to genetic counseling and testing in Slovenia and the second, to investigate the pattern of BRCA1 and BRCA2 mutations in our country, where the migration of population is low.

Methods: Candidates for genetic counseling and testing were selected from the records of the breast cancer-screening program. Women with family history of breast and ovarian cancer and men with a history of breast cancer were invited to genetic counseling. They were offered a questionnaire of detailed family history. Based on the family history data, a probability of BRCA1 and /or BRCA2 mutation was calculated, using BRCAPRO mutation probability model (Cancer Gene 3.3 software). When indicated, genetic testing was proposed. After signing the informed consent blood samples were collected and sent for testing to the Vrije Universiteit, Brussels.

Results: Out of 71 women and 16 men invited, 57 women and 12 men came to genetic counseling and filled-in the family history questionnaire. The probability of BRCA1 and /or BRCA2 mutation ranged from 0,00 to 0,83 in women and from 0,027 and 1,00 in men. Altogether 31 blood samples (19 in women and 12 in men) were collected to be tested.

In the first eight slovenian families tested we found a putative splice mutation (IVS 16-2A>G) that has already been reported. Mutation was found in three families, where 8 individuals tested positive.

Results of the rest 11 women and 12 men tested are not yet available.

Conclusion: Very high compliance of women and men for genetic counseling and testing was observed in contrast to our expectations and published data.

A mutation of the BRCA2 gene (IVS 16-2A>G) in three families was found.

We continue to recruit women and men to the study at a rate 2-3 per week. We will reevaluate our series before the presentation at the EBCC-3.

151 POSTER

On what day of the week do patients wish to be treated? Questionnaire to the patients who receive outpatient chemotherapy in Japan

T. Ishikawa[1], T. Kyogoku[1], T. Okuno[1], N. Kono[2], S. Takao[3], K. Wakita[4]. [1] *Nishi-Kobe Medical Center, Surgery, Kobe, Japan;* [2] *Hyogo Medical Center For Adults, Surgery, Kobe, Japan;* [3] *Nakatu Saiseikai Hospital, Surgery, Osaka, Japan;* [4] *Yodogawa Christians Hospital, Surgery, Osaka, Japan*

Purpose: Currently in Japan, for advanced or metastasized breast cancer patients, a growing number of medical facilities have started to use weekly low dose chemotherapy in an outpatient setting. This treatment method is considered to be effective, and at the same time reduces the side effects and maintains the patients QOL. Even though there are great advantages to this treatment, patients are troubled in their daily lives because of the time they must spend in the hospital weekly. To assess how much stress or discomfort the patients are subjected to, we made a questionnaire.

Methods: Questionnaires were sent by letter to 88 Japanese patients with advanced or metastasized breast cancer who received chemotherapy almost every week in the outpatient department. Patients were asked to fill out questions about their physical conditions, emotional distress and social functions. In addition to these questions, their satisfactions with the treatment and requests for the day of chemotherapy were also asked.

Results: 1) About their treatment, 85% of the patients felt their treatment tolerable, but at the same time 71% of the patients felt some degree of distress. 2) After every administration, 79% of the patients complained of some troubles for about three days. Major complaints included nausea, fatigue, and the time consuming process. 3) Only 47% of the patients wished to be treated on a certain day, though, 64% of the patients who have jobs wished to receive treatment on their day off. The major reasons for the choice of day, was that they did not want the treatment to interfere with their jobs or disturb their families. 4) Half of the patients answered that they would come to the hospital on a day designated by the physician and had no desire for a certain day of treatment. 5) There was no tendency to a certain day of the week, because patients had various requests.

Conclusions: Low dose chemotherapy, which reduces the side effects, makes the outpatient treatment possible. But for this method, patients have to come to the hospital frequently, and their daily lives are hindered by the time loss and the side effects that may occur. To improve the QOL of the patients receiving frequent chemotherapy, we should design schedules to fit each individual's life- style and degree of side effects. However, half of the patients did not insist on any definite day for their chemotherapy and they tend to make their life styles fit the schedule of the hospital.

152 POSTER

Comparative phraseology study to investigate women's preference in the wording of lifetime and age specific risk of developing breast cancer

S.J. Wright[1], M.G. Wallis[1], J. Barlow[2], R.N.G. Naguib[3]. [1] *University Hospitals Coventry & Warwickshire NHS T, Warwickshire, Solihull & Coventry Breast Screening;* [2] *Coventry University, Psychosocial Research Centre, School of Health & Social Science;* [3] *Coventry University, BIOCORE, School of Mathematics & Information Sciences*

The aim was to investigate and compare women's preferences in the phraseology of lifetime and age specific risk of developing breast cancer in the UK and Finland to inform attendees at Family History clinics.

Random sampling techniques were used to recruit women from 5 geographical regions within the UK and from 3 Oulunl**ni principalities in Finland. Each woman was asked her preference between positive and negative wording of lifetime risk, and between three alternate ways of phrasing age specific risk (Percentage, Ratio and Description). The effect of order of presentation of the statements was balanced by using 6 different orders generated according to a Latin Square design. Data were collected through self-completed, postal questionnaires.

Completed questionnaires have been received from 136 women in the UK and 188 women in Finland. Respondents had median ages of 42 and 47 years in the UK and Finland respectively. Mean age was significantly higher in Finland ($p<0.0005$).

Lifetime risk: Significantly more UK women preferred the positive phrasing (76%) compared with negative wording (24%;chi squared=36.57, $p<0.0005$). Conversely, Finnish women preferred the negative phrasing (78%) compared with positive wording (22%; chi squared=54.04, $p<0.0005$).

Age specific risk: 44%, 19% and 37% of UK women preferred the Odds, Percentage and Description wording, respectively. A significantly lower proportion of women preferred the Percentage option (chi squared=12.82, $p=0.002$). In Finland, 27%, 13% and 60% of women preferred the Odds, Percentage and Description wording, respectively. A significantly higher proportion of women preferred the Description option (chi squared=60.43, $p<0.0005$). Preferences were not affected by age or order of statement presentation ($p > 0.05$).

There is a significant difference in choice across the countries (chi squared=18.90, $p<0.005$). Therefore the choice of phraseology in the Family History literature may need to reflect cultural biases.

153 POSTER

A review of breast cancer RCT recruitment data

N. Ahmed, T. Stevens, S. Ahmedzai. *Academic Palliative Medicine Unit, K Floor, Division of Clinical Sciences, Royal Hallamshire Hospital, University of Sheffield, Sheffield, South Yorkshire, UK*

Background: Increasing participation rates particularly to Phase III Randomised Controlled Trials (RCTs) has been identified as a priority (Cavalli et al, 2000). Reviews of breast cancer clinical trials have found numerous and in some cases, arbitrary, eligibility criteria (Begg and Engstrom, 1987) with consequent concerns about generalisability and slow rates of accrual.

Objectives: To review randomised controlled trial patient recruitment data of newly diagnosed breast cancer patients.

Methods: Within the North Trent region there are about 20 ongoing RCTs which focus on improving both survival and quality of life for women with breast cancer. The inclusion and exclusion criteria of each RCT were examined and compared with actual accrual of 130 consecutive newly diagnosed breast cancer patients. A statistical model was developed to predict how changes in inclusion and exclusion criteria would affect subsequent accrual.

Results: (1) Many inclusion and exclusion criteria are arbitrary. (2) The predictive model showed that changing inclusion/exclusion criteria can increase overall accrual and representativeness. (3) Guidelines need to be developed to improve the data recorded in the patients medical records regarding RCT recruitment. (4) The methodologies of the study could be extended to review other clinical data sets in other diseases.

References

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154 POSTER

Predictive testing for hereditary breast and ovarian cancer (HBOC): psychological impact and health related behaviour in the year following the communication of the predictive test result

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In Leuven, predictive genetic testing for HBOC has been available as a clinical service since the end of 1997. In the context of a multidisciplinary approach, test applicants are offered pre- and post-test psychological counselling. Longitudinal psychological research, embedded in the clinical service, is aimed at establishing a baseline evaluation of the testees and at assessing the psychological impact of predictive genetic testing. At present, follow-up data for the first year after predictive testing are available for 38 women (21 carriers and 17 non-carriers).

The mean general distress levels of carriers and non-carriers were not significantly different during the pre-test period nor one year after predictive testing. Moreover, the levels were not higher (some even lower) than in the general population. Except for the STAI-State score that decreased over time, no significant differences were found between pre- and post-test measures.

Most of the carriers who opted for regular medical examinations followed the screening recommendations. About 10% of the carriers had a prophylactic mastectomy within the year after the test result. More than two thirds of the remaining group of carriers stated that they would not have a prophylactic mastectomy in the future. Of the carriers above 35 years, 37% already had an oophorectomy before applying for predictive testing whereas 44% had prophylactic oophorectomy after genetic testing.

155 POSTER

A psychosocial support program for women with primary breast carcinoma in Korea

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Purpose: To our knowledge, there had been no evidence for the efficacy of psychosocial intervention among Korean breast cancer patients. The objective of this study was to determine the effect of a psychosocial group intervention in reducing psychologic distress and enhancing coping in this population.

Methods: The patient selection criteria were age younger than 70 years, having any postoperative adjuvant therapy, and surgery undergone within the previous 3-6 months as of the start of the study and there were 30 patients eligible for this criteria. There was no wait-list control group because any eligible patient did not want to stay in wait-list control group. Therefore a one group pretest-posttest design was used. We conducted a 8-week, structured, psychosocial group intervention, which used psychoeducational strategies combining education and psychological support. Subjects were assessed for psychological distress and coping by administering the Beck Depression Inventory(BDI) and the Ways of Coping Checklist-Revised(WCCL-R) at the baseline and at 8 weeks.

Results: Thirty patients were participated and 20 results of them were used for analysis as appropriate. The posttest results showed significantly lower scores than the pretest ones for depression on the BDI($p<0.001$), and for avoidance ($p<0.001$) and wishful thinking($p<0.001$) on the WCCL-R. Also the total score of coping on the WCCL-R showed a significant difference after the intervention($p=0.051$).

Conclusion: Despite of some limitations, the results of this study suggest that a short term pshchosocial group intervention produces a significant improvement in the quality of life of patients with primary breast carcinoma in terms of managing depression and coping.

156 POSTER

Patient's personality and breast cancer treatment: the development of the complex psychological diagnostics and therapy

J. Malova. *Russian Scientific Centre of Radiology, Psychological Rehabilitation, Moscow, Russian Federation*

Background: The humanistic approach is closely linked with the understanding of the psychological needs of the cancer patients. Breast cancer patients mostly can't cope with their psychological problems without special individual psychological help. For the optimizing the psychological care we have to define: the group of the psychological risk, the risk factors and when they appear in disease experience, the premorbid individual features of the patient's personality, including her motivation, and their changes under influence of the cancer and it's treatment, the structure of the "Image of the Illness", the type of brain reprocessing of the verbal and non-verbal information. Psychological therapy, based on the analysis of the patient's personal resources is effective and manages better quality of the life.

Procedure: In the group of breast cancer patients (N=100) we used psychological diagnostics for definition of the anxiety level, PTSD, structure of motivation, "Image of the Illness", complex neuropsychological diagnostics, drawings like the method of psychological diagnostics. 82 patients needed the psychological help. We used two kinds of the complex methods of the psychotherapy: based on the verbal cognitive therapy (group a, N=41), based on the work with images (group b, N=41). In both groups we had patients under different kinds of treatment (surgery, chemotherapy, hormonal and radiological treatment). The effectiveness of the therapy was measured with the retest.

Results: The effectiveness of the different kinds of the psychotherapy depends on both: premorbid personality and individual type of brain reprocessing and the kind of cancer treatment (the patients with hormonal treatment had positive effect in 75% cases in group b in comparison with 0% in group a). The behavioral therapy and social rehabilitation are useful in 85% of the patients. Art-therapy and work with images is effective in the great amount of the breast cancer patients.

Conclusions: The humanistic approach has to pay more attention to the individuality of the patients, especially in the process of the optimization of the psychological care and the contact with the patients. The experience of the effective psychological care could be used in all the contacts of professionals with breast cancer patients.

157 POSTER

Iranian women's beliefs toward breast cancer: a qualitative interview study

I. Ghaderi, E. Fakhrejahani, A. Kaviani, N. Mehrdad. *Iranian Academic Center for Education, Culture and Research, Iranian Center for Breast Cancer*

According to some studies that show Iranian breast cancer patients are relatively younger than their western counterparts and mostly have advanced diseases,it seems that several undefined factors can influence women's health behaviour and result in low participation rate in prevention and treatment programs.Hence,understanding women's current beliefs may help by uncovering misunderstanding,conceptual gaps,and areas of concern.This study had two stages and designed to investigate a group of middle class women's beliefs about breast cancer and health related behaviours.The first stage consisted of individual's exploratory interviews with medical field specialists,sociologists and religious professionals as well as some authorities in public health administrations.In the second stage 50 rural women between age 19 and 52 participated in the focus group discussions according their education and employment status. Interviews were guided on the basis of an open-ended semi-structured questionnaire designed regarding the results of the first stage. Almost all women believed that breast cancer is a progressive disease and it has benign and malignant forms. In the latter unless treated early,grows, spreads and eventually kills.Most of them did not have clear conception about the causes of breast cancer but they expressed that genetic,infection,personal hygiene, anxiety and stress can play role in breast cancer formation.Majority of these women knew common breast cancer symptoms, however, pain was given greater prominence in this respect.Although many of the women were familiar with screening procedures, many statements reflect a general lack of belief in preventive services; rather, health care is considered as a service for disease.The majority of the women stated that fate has dramatic and inevitable role but it can be changed if patient makes effort to be cured. Furthermore, it is believed that some religious customs and attending holy places have influence on disease course and its outcome.Some women cited persuasive role of family members especially husbands in most situations.Because of modesty and embarrassment, almost all women prefer to be visited by same sex doctors and religious beliefs do not have that much effects expected in this society.This study shows the need to evaluate culture and religious factors attributed to breast cancer related health behaviour with a qualitative questionnaire in a population of all Iranian ethnic communities.

158 POSTER

Patient satisfaction with early discharge with an axillary drain in situ after breast cancer surgery

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The purpose of this study was to assess patients views regarding early discharge with an axillary drain in situ after surgery for breast cancer.

Patients with a diagnosis of breast cancer were counselled regarding early discharge with a drain by the surgeon and breast care nurse. This was supplemented with an information leaflet. Because we wanted to identify the factors which patients felt were important in enabling them to reach a decision, a pre and postoperative questionnaire was devised with the help of the Consumer Involvement and Information Unit to avoid leading questions. The questionnaires were semistructured to look at factors influencing patients decisions and assessed patient satisfaction with the early discharge process. Free text comments were also encouraged. Length of stay and postoperative medical information was also collected which is reported separately. Preoperative questionnaires were completed by 42 patients. Posoperative questionnaires were sent to all these patients 6 weeks after surgery and were returned by 37 patients.

The 3 most important factors which influenced a patient's decision to consider early discharge preoperatively were good information (88% of respondents), having a telephone at home (76%) and easy access to the General Practitioner (GP, 69%). Access to the district nurse and hospital staff were also important. The postoperative questionnaire assessed the satisfaction of patients with various aspects of their care and the degree of postoperative support received. All 37 respondents were either satisfied or highly satisfied with their treatment in hospital and importantly, all felt involved to some extent with the decision to be discharged early. Only one patient was dissatisfied with the support from the GP and only one other patient was dissatisfied with all the nurses and hospital staff with regards to home support. This latter patient developed a seroma which required repeated aspiration.

In conclusion, the majority of patients were highly satisfied with early discharge with their drain in situ. Important factors which contributed to this were good information and clear lines of access to doctors and nurses.

159 POSTER

Oncology nurse as breast care nurse in a diagnostic breast clinic

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The diagnostic breast clinic is a referral center for the investigation of clinical or mammographic finding of the breast. In addition women at high risk of breast cancer may have periodic breast examinations and information regarding genetic testing and the use of HRT. Every woman before surgery is consulted by a multidisciplinary team including surgeon, oncologist, radiologist, breast care nurse and social worker. During the last year 9068 breast examinations were performed, 2515 new women were referred and 280 new breast cancer patients were diagnosed. 7185 specialist nursing intervention were done: 3604 providing information, 1494 inter-disciplinary coordination, 728 needle biopsy assistance, 152 blood tests, 919 reports on tests results and 288 support interventions. According to our experience the population who needs the most intensive qualified nursing intervention is the group of newly diagnosed cancer patients. The anxiety and confusion associated with the diagnosis may reduce the women ability to participate in meaningful collaborative decision making. Professional providing of updated information and emotional support are vital. As the qualification and education required for breast care nursing in Israel is not well established we built a model of an oncology nurse to be the leading breast care nurse of the diagnostic breast clinic. Postgraduate oncology training and experience at oncology ward give the nurse the most qualified skills to provide information and support to newly diagnosed breast cancer patient.

We conclude that the oncology nurse leading the breast care nursing in the diagnostic breast clinic provides the optimal qualified care required.

160 POSTER

Follow up of women during HRT

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There are more and more women in the world, and with us as well, undergoing hormone replacement therapy (HRT) in order to prevent the effects of menopause.

Gynecologic diseases and breast diseases of the patient must be taken into consideration when HRT is prescribed. It is well known that the only contraindication for HRT is hormonal dependent breast carcinoma.

Gynecologists who are in most cases prescribing HRT frequently forget that fact and don't refer women to breast examination before starting with HRT.

In 10-28% of women density of glandular tissue increases HRT what is the second important reason for mammography before HRT. Such glandular density makes the analysis of particular structures in the breasts difficult and can prevent breast cancer to be discovered. It is well known that the HRT is connected with a mild increase of breast cancer risk and that it increases with the length of the therapy. It is therefore recommended that besides the regular gynecological examinations breasts should be controlled as well.

A survey was performed at our Polyclinic among 50 women undergoing HRT. They were asked nine simple questions: age, who recommended HRT, when was it recommended, reasons for therapy, tests performed before starting HRT, were they acquainted with the advantages and disadvantages of HRT, when were they referred to their first breast examinations, how frequent were gynecologic and breast controls. The results were the following: the average age of the examinees was 52.6, in 94% of cases gynecologist prescribed HRT, most women were on HRT because of vasomotor symptoms and osteoporosis. According to our survey all women were examined by gynecologist, only 18% underwent pelvis ultrasound, in 22% CBC with coagulogram was done, 16% underwent densitometry and 60% mammography. It might be significant that only 18 women (36%) underwent mammography before starting HRT and 21 (42%) did it during HRT. As much as 10 women (20%) underwent mammography on their own initiative. All examinees followed regular gynecologc examination while breast control was sporadic in 14% of women.

Regarding recommendations for HRT we found that the results of our survey are devastating. Therefore we should not be surprised when we meet women during HRT with breast cancer or cancer of female reproductive system which were there even before they started HRT but had not been detected in time.

161 POSTER

Breast reconstruction, the first step to woman rehabilitation

R. Ferrario[1], L. Bedodi[2]. [1] *Istituto Nazionale Tumori, OCR, Milano, Italy;* [2] *Rehabilitation therapist and osteopath (TFR) Istit, Italy,*

Plastic surgery used in oncological context offers the patient, the benefit of a reconstruction. The cancer patient experiences a complex situation where factors such as the altered body image interact with therapy, and personality characteristics. A wide literature shows that increase in requests for reconstruction attempt to resolve, affective and psychosocial problems. In breast cancer this implies a simultaneous or deferred breast reconstruction. The diagnosis of cancer, the surgical operation and subsequent therapy, have a considerable impact on quality of life of mastectomized women. The loss of a breast in developed countries is seen and experienced as severe mutilation of sexuality and maternity, sufficient to cause serious psychological disturbance such as anxiety and depression. Many variables have to be considered when advising the patient about reconstruction. We have to take into account the experience of having cancer, where pain,fear and uncertainty about the future, and confronting the imminence of death, contest with a self image where body image can not be separated from the entire personality. The body is seen as basic instrument to construct awareness of the world and establish relationship with the others. After mastectomy the woman uses an external prostesis, but no survey has shown satisfaction rates higher than 60%. Reconstruction is an important step in rehabilitation. Request for it should be assesed by a multidisciplinary team comprising: doctor,nurse,physiotherapist and psychologist. There is an advantage in laying the foundation for reconstruction as the breast is removed because the sense of mutilation is reduced, while in deferred reconstruction where women are aware of the mutilation, there is more time to contemplate/decide the resources available. In our Institute of more than 1600 breast operation over the last two years; the insertion of expander increased from 196 to 244, and the substitution of the same with a definitive prostesis increased from 134 to 208. Reconstruction with authologous flap (operations requiring more surgical, caring and rehabilitative resources) have remained more or less constant. In all these cases, rehabilitation begins pre-op and continues through post-op to follow-up. A study has begun to asses the immediate outcome during and after insertion of the expander to evaluate the mechanical parameters in order to reduce tension in the soft tissues and make the reconstruction more functional.

162 POSTER

The subsequent development of breast cancer in relatives older than index patient

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Introduction: The protocol of the management of breast cancer includes a detailed family history with or without subsequent surveillance of other family members. This is usually concentrated on relatives younger than the presenting patient. We have investigated, in a prospective fashion, the subsequent incidence of breast cancer in family members who were older than the index case at the time of diagnosis.

Methods: The breast care nurse surveyed, by postal questionnaire, 95 patients diagnosed with breast cancer below 45 years of age. Seventy-five age matched female patients who had undergone laparoscopic cholecystectomy (LC) during the same period were also surveyed. Patients were asked to record in detail the subsequent development of cancer in members of the family who were older than they were at the time of their surgery. No additional screening surveillance was performed on family members.

Results: 24 LC patients (25%) returned the questionnaire. Median follow-up was 25 months (range 6-48). None had a relative diagnosed with breast cancer since their LC. Those having had surgery for breast cancer returned 65 questionnaires (68%). Median follow-up was 31 months (range 4-144). Within that time 9 older relatives of 7 (10.8%) of our patients developed breast cancer. The median time to development of the disease was 48 months (range 1-64). Therefore 1 in 9 of our patients, younger than 45 years at the time of diagnosis, had older relatives who subsequently developed breast cancer. However 21 patients, 1 in 3, had a family history prior to developing breast cancer.

Conclusions: The incidence of subsequent development of breast cancer in older relatives, in this series, approaches that of the expected incidence in the general population (1 in 10 - UKCRC). Larger numbers are required before any conclusions can be drawn but there appears to be no indication to screen family members older than the index case at the time of initial presentation.

163 POSTER

Responding to the information needs of women at the time of treatment completion-a pilot study

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Consumer focus groups conducted by the Inner & Eastern Melbourne BreastCare Consortium (IEMBCC) indicated that treatment completion was a time when women felt vulnerable and had information needs that were not being met by clinicians treating them. This pilot study conducted by the IEMBCC aimed to develop and trial an information package provided to women on completion of treatment for early breast cancer.

A highly consultative process was undertaken for the development of the package. An expert group (a multi-disciplinary group of health professionals and a consumer) reviewed a large number of written resources sourced from local, state, national and international organisations. The resources were reviewed using the following criteria:

- information should reinforce that provided by clinicians
- assist women to achieve optimum health
- encourage women to utilise support services
- address issues such as sexuality and fear of recurrence

The shortlist of resources selected by the expert group was then reviewed by 2 groups of consumers who rated the resources according to how essential they were for women completing treatment. Results from the 2 consumer groups were aggregated, resulting in a selection of resources for inclusion in the information package. The final package comprised a total of 19 resources.

Five health care providers distributed the package to women upon or around the time of completing radiotherapy treatment. Twenty-three women participated in a telephone interview conducted 6 to 8 weeks after receiving the package. Sixty-five percent of those interviewed either read all or selected resources thoroughly. The remaining women (35%) read parts of all or some resources. Twenty-two percent of women had a partner, other family member or friend who also read the package.

The women's response to the package was overwhelmingly positive and results reflect that women are able to select resources that are relevant and of interest to them. Many women also indicated that the package contained resources that they would have preferred to receive earlier in their treatment. Health care providers also responded positively to the package indicating that it was comprehensive and encouraged a continuing association with their service.

164 POSTER

Introducing multi-disciplinary care: leading the medical profession through the change process

C. Scott. *Inner & Eastern Melbourne BreastCare Consortium, The Alfred, Victoria, Australia*

Aims: The Breast Services Enhancement Program was established by the Victorian Department of Human Services in 1999 to improve the quality of breast care services. One of the priority areas is the introduction of multi-disciplinary (MD) models of care.

An action research study was conducted during the implementation of MD care into a number of breast care services. The research addressed:

– The role of the change agent in the introduction of MD care into the management of women with breast cancer

– The preparedness of the participants (medical & surgical professionals) to participate in the change process

Methodology: An action research methodology, based on Lewin's cyclic model (Burns 1994) was utilised. Many sources of data informed the project including:

Observation, face to face interviews, workshops & informal contacts. Interpretation of the data was based on the development of grounded theory (after Glaser and Strauss 1967).

Results: The requirements for clinical practice (for which medical professionals are well prepared) were found to be very different from the requirements for considering & undergoing change (for which they are less likely to be prepared). Medical professionals reported difficulties when asked to think about how to improve or change current services. Such requests required a thinking style which was contrary to their habitual thinking styles. The training & work practices – particularly of surgeons – were also found to be associated with behaviours that lower risk and provide protection. The introduction of change however, implied the need to take risks.

Multi-disciplinary models of care were found to challenge the values of medical professionals. As well, the rewards of engaging in MD practice were found to be less enticing than the rewards attached to 1:1 clinical contact with patients.

Conclusions: A number of issues were identified which impact on the ability to introduce change in a medical environment including: the culture of the medical profession, the different rewards offered by change over clinical practice, the implications of MD care in terms of loss of power and authority and the requirements for taking leadership in change.

For the change agent involved in initiating and implementing these changes, a deeper understanding of the factors underlying attitudes to change provided the opportunity to work more effectively in partnership with the medical professionals involved.

165 POSTER

Measuring multi-disciplinary care: meeting the challenge

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Maroondah Breast Clinic is a well-established public multi-disciplinary (MD)breast care clinic in the Eastern suburbs of Melbourne. The team there treats approximately 160 cases of breast malignancy each year.

At an observational level, the performance of the Maroondah team appeared to be consistent with known best practice in the field of breast cancer management, however no objective evidence existed for this.

The team worked with the staff of the Inner & Eastern Melbourne BreastCare Consortium to develop a tool which could be utilised to capture and measure the functioning of the team, and then to compare their performance with best practice in the field. The Clinical Practice Guidelines for the management of early breast cancer (NHMRC 1995) were used to help define best practice in the field.

In the first instance a policy document was developed which expressed the rationale and objectives for the MD case review meeting. These overall objectives were then translated into a set of performance objectives with minimum standards defined for each. Performance Indicators (PI) were then developed against which the team measured their performance at 6-monthly intervals. There were 12 PIs including items such as:

– 100% of new cases of breast malignancy receiving surgery at Maroondah Hospital will be presented at the meeting

– in 90% of cases all of the following information will be provided on the clinical agenda: Unit record number, name of surgeon, date of surgery, summary of surgery to date, grade, type & size of tumour, receptor status, nodal involvement

To date 2 audits have been conducted at 6 monthly intervals. At the first audit it was identified that the performance standard set by the team for inclusion of psychosocial factors in the team discussion had not been met. As a result of this, changes were made to the agenda for each meeting, providing greater prominence to the psychosocial risk factors for each case. This resulted in improved performance in this area as measured at the second audit.

At both audits it was found that a small number of cases had not been presented for discussion, and the team is now reviewing the process whereby new patients are identified and put forward for inclusion in the meeting.

Conclusion: The process of MD care in breast cancer management can be captured and measured by use of an audit tool. Outcomes of such an audit can then form the basis for identifying areas in which performance is at best practice levels, as well as identifying areas requiring improvement.

166 POSTER

Physicians don't see eye to eye with each other on the features of psychosocial support

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Objectives: To evaluate the agreement of physicians on the features of psychosocial support and to demonstrate the predominately existing viewpoints on this critical issue.

Methods: In a survey performed from Jan. to June 2001,a randomly selected samples of physicians filled in a reliable questionnaire on hows and whys of psychosocial support with a 100% response rate.

Results: 213 of 313 physicians participating in the survey were male.There were 113 surgeons, 66 psychiatrists,63 radiologists, 21 oncologists among them. All except 37 (11.8%) believed that psychosocial supportive care is essential for "all" breast cancer patients. 164 (52.4%), 89 (28.4%) and 34 (10.9%) physicians recommended these supportive cares at the time of proper diagnosis,at suspected clinical diagnosis and before surgery,respectively. All except 4 subjects indicated that psychosocial supports improved the outcome of their patients; even 2 of this minority, claimed that it just exacerbated the situation. 52 responders (16.6%) - mostly women (P=0.006) - said that the physicians who are involved in providing psychosocial supports should be female. 223, 218, 190 and 89 subjects recommended psychotherapy, group therapy, family therapy and healing through faith as the care of choice, respectively. Those who believed in drug therapy were not more than 120 (38.3%). Psychiatrists were more common believers of drug therapy and psychotherapy (P=0.007 and P<0.0001, respectively), while family therapy and healing through faith seemed more attractive to psychiatrists and oncologists (P=0.002). In telling the truth to the patients about cancer, most physicians believed that circumstances alter cases. Therefore, they decided on this matter for each individual patient. Interestingly enough, oncologists were more frank in this regard (P=0.03). Only 2 physicians shared the idea that the patient should be kept completely unaware of her disease. Among others, 209 (66.7%) would explain the situation to her without referring to details and 40 (12.8%)would revealed all facts and features of the disease to their patient.

Conclusions: We observed a vast domain of ideas among physicians on the features of psychosocial support for breast cancer patients. This necessitates the academic education of involved physicians on the standard protocols. Further randomized studies are needed to demonstrate any significant differences in outcome of patients undergoing each of these various theoretical and practical standpoints.

167 POSTER

Menopausal status cannot be assessed in a significant number of breast cancer patients

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Introduction: Menopausal status is used to stratify patients for both hormone and chemotherapy in routine practise and for entry to clinical trials.Age 50 is used as menopausal age. Actual menopause may occur between 35 and 60 years.

Aims: To assess actual menopausal status of breast cancer patients using a self administered and nurse administered questionaire.

Methods: A detailed questionaire with information about previous hysterectomy, oophrectomy, menstrual history and use of Hormone replacement Therapy (HRT) was self administered by 5 patients and 5 age matched controls in a pilot study. 30 patients had the same questionaire administered by a specialist breast care nurse or doctor.

Results: The 30 patients and 5 healthy women were aged between 40 and 69 with a mean age of 57 years The self administered questionaire was unsuccessfull. It was not possible obtain accurate information about menopausal status using this method. It was possible to obtain accurate information useing the nurse/doctor administered questonaire. The mean time to fill in the questionaire was 15 minutes. In seven cases (23%)it was not be possible to assess menopausal status. The reasons for this were patient uncertainty about previous hysterectomy/oophrectomy and HRT usage(3 patients) Four patients had started HRT while mensruating regularly and had taken HRT for a mean of 7 years. Hormone levels could not be measured at the time of diagnosis because of their HRT usage.

Conclusion: A significant number of breast cancer patients have an uncertain menopausal status at diagnosis. This may affect responses to both hormone and chemotherapy

168 POSTER

The ideal psychosocial support team for breast cancer patients: controversies prevails

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Psychosocial support is one of the essential elements of the care provided for breast cancer patients, regarding the leading role of such supportive team,it is crucial that the involved physicians reach an agreement on the characteristics of an "ideal team".The present survey aims to describe and compare these existing points of view among Iranian physicians.In this cross-sectional study, performed in the first half of the year 2001, the randomly selected sample of physicians, expressed their ideas toward an ideal. Supportive team throngh a valid questionnaire containing 20 closed questions, the response rate was 100%.313 physicians (113 surgeons,63 radiologist,21 oncologists and 66 psychiatrists) filled in the questionnaire. 68% of them were male. Only 38 of the physicians (12.1%)insisted that the supportive time should be parted from the medical team; while 73 respondents (23.3%) believed that supportive care should be provided by the medical team and 192 (61.3%) said that both sources should be implemented for the psychosocial supportive care. Most physicians of the second group were psychiatrists (P<0.0001).

Overall, respondents commonly (38%) introduced the surgeon as the best and the most suitable manager for this supportive team; while psychiatrists mostly believed that this management is the mare responsibility of psychiatrists (P<0.0001). 50.8% of respondents, especially the psychiatrists themselves (P<0.0001), indicated that the presence of a psychiatrist is essential for an ideal them.

"Is it necessary that the care provider be a female?", 261 physicians (83.4%) said "no"; while women physician more frequently insisted on this necessity (P=0.006). Most respondents indicated that education of the involved physicians and the patient's families are of upmost importance (58% and 49.8% respectively). In addition, they commonly believed that these two groups can provide most effective psychosocial supports (46% and 40.9% respectively).

Biopsychosial aspects of the human being should always be considered and cared for in diagnosis and treatment of patients. It seems that psychiatrists don't share the same views as other physicians about the characteristics of an ideal psychosocial support team. There results show that there is a strong necessity to introduce guidelines for an ideal psychosocial support team and encourage physicians to come to agree with each other on there ideal structures to promote the care and outcome of breast cancer patients.

169 POSTER

Improving breast care services in Inner-Eastern Melbourne a collaborative approach

C. Scott, A. Rodger, S. Galetakis. *Inner & Eastern Melbourne BreastCare Consortium, The Alfred, Victoria, Australia*

The Inner & Eastern Melbourne BreastCare Consortium (IEMBCC) was formed to identify and implement a number of improvements within its member hospitals. The consortium receives its funding through the Breast Services Enhancement Program, established by the Victorian State Department of Human Services in 1999, and which forms a vital part of a 5 year breast disease improvement strategy. Its aim is to improve the accessibility and quality of breast care across the State.

The IEMBCC established a consultative process involving key stakeholders including consumers to identify areas of breast care requiring enhancement.

Three areas for improvement were prioritised:

- Multi-disciplinary (MD)care
- Access to breast care nurses (BCNs)
- Enhancing continuity of care

Within each of these areas a number of projects were developed * some involving major change, others involving small process improvements which were predicted to positively impact on the experience of patients.

Improvement projects selected were driven by the evidence provided in the following Australian documents, which have been endorsed by the National Health & Medical Research Council:

The Management of Early Breast Cancer Clinical Practice Guidelines (1995); Psychosocial Clinical Practice Guidelines (2000); Advanced Breast Cancer Clinical Practice Guidelines (2001).

In the area of MD care, case review meetings were established in 3 hospitals, despite resistance to the introduction of such meetings by some of the clinicians involved.

While the services of a BCN were available to women with early breast cancer, those women with recurrent or advanced breast disease were less likely to gain access to such a service. In collaboration with the University of Melbourne Postgraduate School of Nursing, a multi-centre study was instigated to identify the role of the BCN in meeting the needs of women with advanced disease.

Consumer focus groups reported that information needs of women were not being met at the time of completion of all treatment. A project was undertaken to enhance the continuity of care, by providing for the information needs of women at this critical time. A model involving input from experts in breast cancer and consumers was utilised. The end product was an information package specifically targeted at patients on completion of treatment, which was then trialed in the community. Women expressed high levels of satisfaction with the packages.

Conclusion: A deliberate government policy to improve breast care services supported by adequate initiative funding has resulted in improvements in a)the MD process; b) care of women with advanced breast cancer; c) end of treatment information.

The Program continues.

170 POSTER

Bilateral prophylactic mastectomy - impact, meaning and outcomes for individual women

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The aim of this study is to conduct a retrospective analysis of the impact, from the woman's perspective, of undergoing bilateral prophylactic mastectomy (BPM). Most breast cancers are sporadic, with less than 10% being attributable to a genetic abnormality. However, for women who do have a significant family history or who carry a specific cancer predisposing gene, BPM may be proposed with the intention of risk reduction.

All eligible women who underwent BPM between January 1998 and June 2001 were invited to participate (n=70). Eligibility criteria included women who have a predicted probability of developing breast cancer from their family history of at least 25% or who carry a breast cancer predisposing gene mutation.

Participants completed structured, self-administered, pre-validated questionnaires, containing mainly closed questions with fixed alternative replies, but with some free text to allow expanded commentary. Responses were coded for tabulation.

The end points being studied are quality of life and general health, worries about cancer, impact on body image and sexuality, impact on work and social life, physical effects of surgery and overall satisfaction.

There is paucity of data regarding the impact of BPM and much of the work focuses on the outcome in terms of reducing breast cancer development (i.e. disease orientated), rather than on the personal meaning for the individual women concerned. It is hoped that the recommendations from this study will enable health care professionals to ensure women are appropriately prepared for undergoing BPM and receive optimum, individualised and humane care in the future.

171 POSTER

Empowering patients to make informed treatment decisions based on tolerability, quality of life patient preference. A comparison of letrozole and anastrazole in a multicentre, randomised, single-blind cross over study

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Introduction: Although anastrozole (A) & letrozole (L) are generally well tolerated, side effects can still occur in up 40% of women, particularly those of endocrine and gastrointestinal origin. Their use is increasing rapidly as they have demonstrated better tolerance than Megestrol & Aminoglutethimide, and greater effectiveness than Tamoxifen in the metastatic and neoadjuvant setting. To engage large numbers of individual women in treatment decisions which may affect their daily lives, it is an important humanitarian issue to know which drug is better tolerated, preferred by the majority and associated with a highest quality of life (qol).

Methods: 72 postmenopausal female patients (median age 67 yrs), all previously taken Tamoxifen, gave written informed consent to be randomised in this cross over study. 7 patients were not included in the analysis (1 died, 4 opted not to cross over, in 2 no questionnaires were completed). Of the remaining 65 patients, 34 (52%) received L 2.5mg od, a six day wash out followed by A 1mg od 4 weeks. The other 31 (48%) received the medication in the reverse order. Clinician prescriptions were blinded but patients knew which drug they were taking.

Results: Qol was significantly higher in the L phase versus the A phase measured by the Fact-es on days 1,8&28 (5.1 difference, $p=0.02$). On the last day of the trial, before the patient attended the clinician, an ad hoc questionnaire showed that more than twice as many women preferred to remain on L and than A (68% v 32% $p<0.01$), the most cited reasons being less nausea, hot flushes and GI symptoms. Women choosing L had significantly better qol while taking L, those choosing A had significantly better qol on A. A further questionnaire revealed that 92% ($p<0.001$) of patients welcomed the opportunity to test both drugs, to make the long-term treatment decisions themselves and recommend this to future patients.

Conclusion: The significantly better qol and tolerability of patients on L rather than A was reflected by greater patient preference for this drug.

Patients' welcomed greater opportunities to involve themselves in the decision making process. Furthermore, for the first time, the credibility of patient preference has been substantiated in a clinical trial by its strong correlation with qol. This user-friendly end point, should be considered in future cross over trials as a means to further increase patients understanding of their treatment options.

172 POSTER

Partnering with patients: telling patients their mammographic results while they are in the clinic

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Introduction: Assessing appropriateness, costs, and outcome of informing patients of their mammographic results while they are still in the radiographic clinic.

Methods: One Breast Clinic's quarter-century experience of routinely telling more than 150,000 symptomatic and asymptomatic patients the results of 550,000 mammographic examinations and workups.

Results: Patients with positive or questionable findings were more likely to adhere to recommendations, return for further study, or come back for follow-up. Patients with negative results were more willing to return annually because they know they will not have to wait and worry about their x-ray findings. Referring physicians appreciate being relieved of the burden of informing patients of negative results or giving bad news to patients. Estimated costs were no more than answering patients' worried phone calls.

Discussion: Our 25-year experience has shown that giving patients both positive and negative results assures adherence to advice, improves care and follow-up, enhances relations with referrers, reduces the chance of litigation, and is as cost-effective as mailing notices or asking the referring physician to tell patients their results.

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Breast complaints: which cause more distress?

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Breast pain, a common problem in the setting of both primary care and breast clinic, is occasionally sever enough to interfere with quality of life and then sufficient to justify careful investigation and treatment. This study was designed to evaluate the psychiatric characteristics of this group of patients with asymptomatic women referred for screening or with the complaint of breast lumps.

A total number of 600 Iranian women (200 patients in each group), who had attended Iranian Center for Breast Cancer surgery clinic for the first time, were interviewed. They were asked to evaluate their overall health and quality of life during past week of visit, giving themselves a score of 1 to 7.Their demographic characteristics and past medical and family histories were also obtained.

Although there was not significant differnece between groups considering any signs of anxiety, depression or impairment in function,overall health during past week had significantly lower rank in the group of patients with breast pain ($p=0.000$) even after eliminating the effect of age as a confouder ($p=0.01$). QOL during past week did not show significant difference ($p=0.07$), but it had also a lower rank in this group. Family history of breast cancer was less common among women with breast pain in comparison with other two groups ($p=0.001$). The frequency of high educated was 24% among patients with mastalgia, while 36% in asymptomatics and 40% in patients with mass($p=0.03$).

Our data indicates that however breast pain is not as important as breast mass for clinicians, but it causes more distress for patients. This study shows that the lack of information about breast cancer have a role in how much breast complaint effect daily life. Surgeon-patient relation and the necessity of reassurance were also affirmed.

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Does primary surgical treatment influence quality of life in breast cancer patients?

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Background: Over the last decades, breast conserving therapy proved to be just as safe and less traumatic compared to mastectomy for surgically manageable breast cancer. However, the impact of these treatment modalities on several important aspects of quality of life (QoL) remains unclear. The purpose of the present study is to compare the long-term impact of both surgical approaches on QoL in patients with identical tumor stages and to assess the value of the standard QoL questionnaires in this matter.

Methods: From August 1999 until May 2000, 152 breast cancer patients of the I. Frauenklinik, Ludwig-Maximilians University Munich were answering QoL questionnaires, as part of routine follow-up examinations. The pairs of patients, each consisting of one patient after mastectomy and one after breast conservation, were matched according to the highest degree of equivalence in tumor stage. All patients had been initially treated for stage I-III breast cancer without evidence of distant metastases. The QoL was evaluated by using the QLQ-C30 questionnaire version 2.0 of the EORTC Study Group on Quality of Life. Additionally, we implemented seven questions about the patients' satisfaction with the primary surgical treatment modality as viewed from their current perspective. After a median interval of 46 months following primary treatment, the QoL questionnaires were answered.

Results: Tumor stage, prognostic factors, and adjuvant systemic therapy were well equilibrated between both groups. For none of the QoL items measured by the QLQ-C30, we could find a statistically significant difference. Our additional questions, however, revealed that patients in the mastectomy group were less satisfied with the cosmetic result of their primary operation ($P < 0.0001$), were more likely to feel basic changes in their appearance ($P < 0.0001$), and were more likely to be emotionally stressed by these facts ($P < 0.0001$) compared to the breast conservation group. From their perspective at the time of completing the questionnaires, 11 patients in the mastectomy group (15%) would decide differently about the surgical treatment modality, whereas only 3 patients (4%) in the breast conservation group would chose the other treatment option ($P = 0.025$).

Conclusion: Apparently the primary surgical treatment modality in breast cancer seems to have no long-term impact on the general QoL, whereas mastectomy may cause certain body image related problems. In order to detect differences in satisfaction and adaptation with the primary surgical treatment modality, the use of standardisized QoL questionnaires alone may not be sufficient.

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Patient orientated evaluation of the EORTC QLQ C-30 and the EORTC QLQ BR-23

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Introduction: The study tended to evaluate the EORTC QLQ C-30 and the EORTC QLQ BR-23 on basis of a patient orientated concept integrating Antonovsky's Salutogenesis and a multidimensional approach on QoL. The study had been carried out in co-operation between the Institute of Medicine/Nursing Pedagogics and Nursing Science (Charit*, Berlin) and the Oskar-Ziethen-Hospital, Berlin.

Procedures: 5 patients diagnosed breast cancer 12-18 months before starting the study have been interviewed in qualitative problem centred interviews about the instruments to measure HrQoL (EORTC QLQ C-30/BR-23), their subjective view of QoL, the individual coping process and their individual estimation of disease and treatment. The interviews had been analysed interpretative-reductive and compared with the main criteria derived of the theoretical framework. Categories and criteria of the theoretical framework were also the basis to analyse the instruments out of theoretical perspective. The results of the interviews and the theoretical analysis had been combined for conceptual prepositions to improve the handling and the use of the instruments.

Results: The instrument to measure HrQoL of breast cancer patients is deficit orientated though there are many resources mentioned and used by the patients. The influence of the resources can't be ignored because there are obviously interdependencies between them and the QoL. Patients resource developement and recognition are important strategies which should be improved in the therapeutic process. The subjective view of the patients isn't quiet enough represented by the instruments regarding the real perceived QoL. The questionnaires are useful to measure treatment side effects but not really sufficient to get informations about individual QoL. The additional potentials of the questionnaires to improve doctor-patient-relationship aren't fully uesd.

Conclusions: Therefore an additional guide to use the EORTC QLQ C-30/BR23 had been developed. This seems to be a practicable and ingenious way to integrate new concepts and patient orientation without changing a validated and reliable instrument which is used in different cultural and clinical settings successfully. Nevertheless this can develop new potentials of the HrQoL measurement.

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Speaking the same language: do doctors, referrers, and patients interpret the meaning of the mammographic report in the same way?

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Purpose: Determining how well radiologists and referring physicians explain and understand the meaning of probability words in mammographic reports, how well they convey this meaning to referring physician and patients to convince patients of the importance of adhering to medical recommendations.

Materials and Methods: After conducting a mega-analysis of the medical literature, we sent probablity surveys to 50 radiologists, 50 referring physicians, and 50 women. Each group was asked to assign its understanding of the numerical meanings of 50 "commonly" used probability words (for example, "usually,""frequently,""often,""likely," and "rarely"), particularly as they are used in a mammographic report.

Results and Discussion: Each group disagreed with the other two groups' numerically assigned meanings and "frequently" disagreed with the meanings assigned by members of their own group.

Conclusions: Doctors need to learn how to talk to each other and to patients. Numerically defined ranges of terms and probability words would help referring physicians and patients understand mammographic reports, so that patients would act promptly upon medical advice. Improved communications between radiologists, referring physicians, and patients would improve patient care, follow-up, adherence to advice, and outcomes.

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Conservative surgery of the breast cancer in elderly women: Our experience

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Background: The incidence of breast cancer rises very much in the elderly, as stated by the SEER study of the National Cancer Institute which highlighted that the incidence is 72.8/100000 $<$ 65 years women and 444.7/100000 in $>$65 years women. It is expected that most women presented to the symptomatic breast clinic have cancer. Treatment of the old patients might be influenced by concomitant diseases and Hormone enrangement.

Objective: To evaluate the choice of treatment for elderly (>/= 70 years) women suffering from breast cancer.

Methods: A retrospective study of all new breast cancer referrals, aged $>$70 or older at presentation (middle age 77 years). There are 86 referrals: 80 pts were in first or second stage, 6 pts were in locally advanced stage (III-IV). Sixty-nine pts underwent conservative surgery (50 QUART, 19 TART); 10 pts underwent Madden radical mastectomy; 3 pts refused surgical treatment and it was set up only ormonotherapy (Nolvadex 20 mg/die); 4 pts refused any treatment and were missed. For the axillary treatment: no treatment for 54 pts (stage T1a, T1b, T1c) whit negative lymph nodes; lymph nodal sampling for 17 pts (stage T2) with clinical negative lymph nodes; full axillary emptying for 8 pts (stage T2) with positive lymph nodes;

Results: At the five years follow-up 6 pts surgically treated are died: 4 (stage II and N+) for metastatic disease, 2 for concomitant diseases; 62 pts (54 stage I and 8 stage II) were in clinical remission; 8 pts (stage II) were in steady state; 3 pts (stage II and lymphnodes +) were in metastatic disease.

Conclusion: Our experience confirmed that the elderly patients with breast cancer can be treated with conservative surgery as much as the young ones, because the treatment of breast cancer is not related to the age and/or to the cancer size a whole preoperative study of patients and an accurate evaluation of the life expectation. Can obtain an adequate residual life after conservative surgery in elderly patients.