to monitor the patients for adverse reactions, so therapy can be stopped before the toxicities become life-threatening.

11 INVITED

Cosmetic and functional sequelae related to breast cancer surgery

M.R. Christiaens. *Department of Surgery-Senology, University Hospital Gasthuisberg, Leuven, Belgium*

Only last decade, local treatment of early breast cancer has evolved from ablative to breast conservation procedures. Although, breast conservation with radiotherapy still results in moderate or unacceptable cosmesis in 20 tot 25% of the cases. Not including radiotherapy modalities, the factors influencing cosmesis are related to the localisation of the tumor, the diameter of the tumor and subsequently the volume of breast tissue resected, the type and orientation of the incision and continuous or discontinuous incisions to breast and axilla. Most of these factors influencing cosmesis are inversely related to local control and recurrences are probably the most important 'sequelae' since they result in mastectomy in the majority of cases.

Axillary dissection has been debated with emphasis to the extent of the dissection and relation to shoulder function impairment and lymphoedema of the arm and the breast. To this, sentinel node biopsy, in selected cases (without axillary dissection), may be of importance for women with major physical arm activities – who before had to give up their activities, without impairing their chance for cure.

It is clear that multidisciplinary decision making and selection of patients for either type of surgery or combined treatment is of the utmost importance to avoid late sequelae and provide excellent tumor control.

12 INVITED

Late sequelae of radiotherapy in breast cancer

J. Jassem. *Department of Oncology and Radiotherapy, Medical University of Gdansk, Poland*

Radiotherapy has traditionally played an important role in the management of breast cancer. In operable disease it has been used as an adjunct to mastectomy and in inoperable locally advanced tumors ñ as a definitive care. The role of radiation has considerably increased with a common substitution of mastectomy by a conservative approach including tumor excision followed by breast irradiation. Since patients managed by breast conserving therapy have early tumors and favorable prospects of long-term survival, it is necessary to evaluate thoroughly late complications produced by this method. Based on the accumulated experience it may be stated that the risk of serious normal tissue damage produced by this approach is relatively low. Common side effects include breast edema, breast fibrosis and pain. Less frequent complications are pneumonitis and rib fracture. The irradiation of regional lymph node areas (axillary, supraclavicular, parasternal) may result in more disabling complications such as arm edema, impaired shoulder mobility, brachial plexopathy or cardiac injury. The major risk factors for late postradiation complications include total and fraction dose, treatment volume and the use of chemotherapy. For this reason the incidence of late complications is increased in locally advanced breast cancer patients in whom usually higher radiation doses and larger treatment volumes are necessary to produce effective tumor control.

13 INVITED

Late psychological sequelae of breast cancer

Peter Maguire. *CRC Psychological Medicine Group, Stanley House, Christie Hospital, Manchester, M20 4BX, UK*

Up to 35% of women with advanced breast cancer develop a major depressive illness and/or generalised anxiety disorder. While there is a strong link between the number and severity of patients' concerns and the development of these disorders those so affected are least likely to disclose their concerns to doctors or nurses. Even those who are not affected disclose less than half of their concerns. The reasons will be discussed and guidelines offered.

Wednesday, 30 September 1998 09:30-11:30

SYMPOSIUM

Communication – who and how to bring the news

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14 INVITED

Training in communication

Darius Razavi. *Service Médico-Psychologique, Hôpital Universitaire Saint-Pierre, rue Haute 322, B-1000 Brussels, Belgium*

Good communication with cancer patients is essential in facilitating their adjustment. For instance, it enables patients to anticipate problems, assists rehabilitation and avoids unnecessary distress. Communication is a complex process because medicine in general and oncology in particular are facing an exponential growth of scientific knowledges, generating difficulties in the process of decision making. This context and the changes of attitudes of health care professionals in favour of a good communication, require an acquisition of detailed knowledges about patients reactions and needs for support. The more health care professionals will attempt to communicate, the more patients will react on a verbal or non-verbal level. These reactions will require additional attention from health care professionals with regard to the patients needs. It is unrealistic to expect health care professionals (physicians and nurses) to support their patients in that way, and break bad news optimally for example, unless they are equipped with the necessary skills through training which is generally still unavailable. The results of two randomized study assessing the effectiveness of training programmes on communication skills, professional stress and attitudes will be presented and discussed.

15 INVITED

Structuring communication in breast cancer care

F.C.E. Postma-Schuit. *Comprehensive Cancer Center Amsterdam, The Netherlands*

Communication plays an important role in the quality of care of cancer patients. The Dutch initiative group of Europa Donna has held a survey into the most important problems in breast cancer care as experienced by patients, doctors and nurses.

A remarkable finding was that patients mentioned communication and information as a major problem area, and not, as might be expected, medical treatment. Nurses reported disturbances in the communication between doctor and patient and among health care workers as a principal problem. Lack of interdisciplinary communication was also mentioned by doctors as one of the main problems.

Recent developments:

Government: Patient rights, including the right to information and the right to complain, are laid down in the Medical Treatment Contract Act (1995).

Health Professionals: Physicians' working groups focusing on breast cancer have started to include patient education and psychosocial care in their guidelines for diagnosis, treatment and follow-up. Checklists on patient education have been developed by nurses. On a local level GP's, physicians, clinical and district nurses co-operate to develop interdisciplinary working agreements focusing on the consistency and continuity of patient education and interdisciplinary communication.

Patients: The breast cancer patients organization has drawn up criteria for quality of care to be used for quality enhancing projects. They want "a seat at the table" in discussions on quality of breast cancer care.

16 INVITED

Preliminary psychometric testing of a comprehensive assessment of satisfaction with care in an oncology institute

A. Brédart, D. Razavi[1], F. Didier, E. Scaffidi, C. Robertson, A. Costa. [1]*European Institute of Oncology, Milan, Italy; CHU Saint-Pierre, Bruxelles, Belgium*

Dissatisfaction with care may substantially contribute to further deterioration of quality of life in cancer patients. However, at present, little is known on patients' perception of quality of care received in an oncology hospital. We developed a Comprehensive Assessment of Satisfaction with Care (CASC) adopting several initiatives for dealing with the social desirability bias commonly reported in that area: detailed aspects of care were considered and two types of rating scales were used. This questionnaire (61 items) evaluates hospital doctors and nurses competence, as well as aspects of the hospital organisation and structure. Consecutive cancer patients discharged from an oncology hospital were asked to complete the CASC at home and to send it back through a self-addressed envelope. Two-hundred and twenty patients were approached over a 9-month period. Only 12.3% of patients did not return the questionnaire. Internal consistency proved very good (Cronbach's alpha coefficient = 0.98). Convergent validity has been evaluated by examining the correlation between scales A and B ($r = 0.71$, p value < 0.0001). Exploratory factor analysis was undertaken on 184 questionnaires. Results of present psychometric testing of the CASC forecast adequate properties. This should be confirmed by repeating these analyses on a larger sample size.

17 INVITED

Culture and communication: Approach to patients in clinical research

Matjaž Zwitter[1], Tanja Čufer[1], Uroš Smrdel[1], Patrick Therasse[2]. [1] *Institute of Oncology, 1105 Ljubljana, Slovenia;* [2] *EORTC Data Center, 1200 Brussels, Belgium*

Background and Objective: to review the current practice of informed consent among physicians actively involved in clinical research for breast cancer and to explore possible influence of cultural setting and of physician's professional background upon the pattern of consent.

Methods: A questionnaire on the practice of informing patients and obtaining their consent for participation in a clinical trial was mailed to 218 physicians – members of the EORTC Breast Cancer Group.

Results: 117 physicians returned the questionnaire. The process of informing patients and obtaining consent is mostly within the guidelines of good clinical practice; still, the level is higher among physicians in Western Europe than among those from Southern and Central/Eastern Europe. Age, gender and training abroad do not influence physicians' attitude. When compared to others, physicians from Western Europe devote more time to inform a patient and obtain consent; nevertheless, patients' refusal to join a trial is more common in Western Europe (28.5%) than in other parts of the continent (19.2%).

Conclusions: Even among highly qualified clinical investigators, clear differences in approaching patients for participation in clinical trials are seen. Cultural background, recent history of human and patients' rights, and physicians' personal attitude may contribute to the prevailing pattern.

Wednesday, 30 September 1998 11:45-12:30

PLENARY LECTURE

How can women influence health policy

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18 INVITED

How can women affect health policy

Jenny Tonge. *Member of Parliament United Kingdom, House of Commons, London SW1 1AA, UK*

(a) Women's perception of breast cancer, images of course of disease, treatment and effect on lifestyle.
(b) Demands made on professionals by women.
(c) Influence of parliamentarians
(d) Influence of media
(e) Charities and self-help groups
(f) Government Action.