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### Patient evaluation of hormone therapy in breast cancer: Quantifying trade-offs between survival gains and quality of life

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**Purpose:** The Patient Preference Interview Study (PPIS) is part of the CRC Under Fifties Trial of Adjuvant Tamoxifen and Zoladex. The aims of the PPIS are: firstly, to develop an instrument that will enable patients to make judgements about how worthwhile the treatment has been in relation to side effects experienced and putative gains; secondly, to determine trade-offs between the experience of taking adjuvant hormonal therapies and the potential benefits of doing so (trade-offs are measured in terms of survival time and survival rates); thirdly, to compare the results of this study with those obtained in the Under Fifties Trial and its Quality of Life Study.

**Method:** Patients are interviewed 6–12 months after completion of two years of trial therapy, using a semi-structured interview and a study tool. The interviews are usually conducted by a member of staff from the local hospital, who has received interview training. Structured notes and an audio-tape of the interview are then analysed centrally.

**Results:** Development of the methodology, study tool and training program will be described, along with preliminary results from the study.

**Conclusion:** By using this new methodology in the context of an ongoing trial, a detailed, quantified evaluation of treatment can emerge for the first time from the perspective of patients who have experienced both the disease and the treatment. This unique study will act as a pilot to enable similar exercises in understanding patient choice to occur.

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### On the way towards integration: A psycho-educational group for breast cancer patients

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Twice a year a psycho-educational group is offered to women with breast cancer without metastases shortly after their operation and adjuvant therapy.

The group consisting of 12 women is lead by a gynaecologist-sexologist and a psychologist, specialized in the counselling of people with cancer. During the 10 group sessions medical, psychological, relational, sexual and social issues related to living with breast cancer are dealt with. Furthermore coping techniques of the participants are made clear to them during the discussion. Relaxation and visualisation are also taught. The women evaluate the program extensively at the end of the course and one year later during a semi-standardized interview. The pre and post test instruments include the Hospital Anxiety and Depression Scale (HADS), the Utrecht Coping List (UCL), the Perceived Social Support Scale (PSSS) and Omgaan met kanker (HDI-O). Summarizing the results from the tests we find a remarkably high anxiety score, mild depressive feelings and extremely seldom a positive optimistic attitude, a good social support and highly controlled emotions.

In contrast with the test results, women state to have more control over their lives and to experience less anxiety, being able to deal with it better during the interview by and independent researcher.

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### Quality of life – An essential aspect in the follow-up care of patients with breast cancer

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**Introduction:** A community based five year field trial (county in Hessa, Germany) aims at improving follow-up care of patients with breast cancer. One central aspect is the quality of life (QL) analysis at defined intervals.

**Methods:** Inclusion criteria: all patients newly diagnosed and operated for breast cancer within the first two study years. QL-assessment (at discharge from hospital and at every follow-up examination): EORTC QLQ C30 plus symptom-specific questionnaires. Quality circle: a group of 20 persons, consisting of representatives of practitioners and hospital staff of the region, patient self-help groups and study coordinators.

**Results:** (interim analysis after 18 months). QL-assessment at discharge from hospital was possible in 80.1% of the patients. 10% were unable to fill in the questionnaire (e.g. mental disease), 9.9% refused. 100% of the practitioners cooperate in organizing follow-up QL-assessment. The quality circle held 7 meetings with a 90% show-up of its members. Members of the quality circle came up with a list of 12 symptom-specific therapies aimed at improving patients' QL (e.g. physical exercise, psychotherapy).

**Discussion:** (1) Our results show that routine QL-assessment is feasible. (2) Symptom-specific therapies were identified that can be applied in response to deficiencies in particular QL-dimensions. (3) In a final step the QL-assessment will be tested as a routine diagnostic tool in a randomized trial to find out if the knowledge of QL influences the treatment of the practitioners.

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### Assessing the psychological functioning and health care choices of adolescent daughters of breast cancer patients

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**Purpose:** Preliminary research and clinical experience indicate that adolescent daughters of breast cancer patients are at increased risk for psychological problems, in part because they must cope with the knowledge of their own increased risk at a time when they are grappling with issues of sexual development. We are currently designing a study with two primary objectives: to examine (1) the psychological functioning of adolescent girls at high risk for a hereditary form of breast cancer, and (2) their attitudes towards predictive genetic testing for breast cancer, preventive treatment options, and other health care behaviours.

**Methods:** We will utilize a case-comparison design to compare 100 families with adolescent daughters in which the mother has been diagnosed with breast cancer to 100 families from the general population. Family members will complete measures of health beliefs and family and psychosocial functioning in a face-to-face assessment. To ensure the validity and relevance of the study design, focus groups will be conducted initially with adolescent girls and their mothers.

**Hypotheses:** We predict that factors related to family coping strategies, parental psychological adjustment, family relationships and family members' attitudes and perceptions about breast cancer and its treatment will be associated with adolescent daughters' adjustment and attitudes.

**Results:** Preliminary data from the focus groups and individual assessments will be presented.

**Implications:** Results of this study will help develop new prevention and psychological programs for breast cancer patients and their families.

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### Implications of social support for survivors of breast cancer

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**Purpose:** In general, the strength of the social support system is an important factor in the long- versus short-term survival of a woman with cancer. This presentation discusses the relationships among social support, coping, quality of life and recurrence among a sample of longer term survivors.

**Methods:** A survey was administered to 178 women survivors of breast cancer who were associated with a university-based program.

**Results:** Significant associations were uncovered among social support (by number and type of contacts) as well as coping style (in fighting spirit) and quality of life as well as recurrence. Accounting for co-variances, women with more dense social support networks and more fighting spirit had enhanced quality of life; paradoxically, only those with less dense networks manifested less recurrences.

**Conclusions:** An intervention designed to maximize the beneficial effects of social support and to minimize noxious social ties will be described.