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Quality of care through the eyes of breast cancer patients – towards a new measuring instrument

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When designing a method to assess quality of care for breast cancer patients as perceived by these patients, a questionnaire should address specifically the needs and ideas of this group [1]. To our knowledge such a questionnaire does not yet exist.

To explore how breast cancer patients define quality of care, 8 focus group discussions (FGDs) with 75 breast cancer patients in 5 different hospitals in the Netherlands were organised. Each FGD lasted 2–2.5 hours. After the FGDs, 65 patients participated in six Concept Mapping meetings (CMMs) in which 81 items, most frequently mentioned during the FGDs were rated on a five-point Likert type scale ranging from 1(relatively unimportant) to 5(extremely important) and structured according to similarity.

The FGDs resulted in over 200 quality of care aspects mentioned by the respondents. During the CMMs, the structuring of 81 aspects resulted in importance scores ranging from 4.68 (direct referral from my GP to the hospital when a suspected lesion is found by the GP or through the breast cancer screening programme) to 1.37 (my doctor should give me information on the possibilities of patient support groups) indicating that the first item is looked upon as most important of the 81 items whereas information by doctors on patient support groups are viewed as relatively unimportant when breast cancer patients define quality of care. Structuring according to similarity resulted in 6 general clusters of items. These clusters can be labelled as period of admission (6 items), focus on patient (9 items), respect for the patient (12 items), time schedule (10 items), continuity of care (10 items) and education (8 items). The average importance scores for these clusters range between 2.1 and 4.68.

Focus group interviews and Concept Mapping meetings were used as a first, important step towards a new quantitative questionnaire for assessing quality of care from the perspective of breast cancer patients. Both qualitative methods resulted in a wealth of data on items this specific patient group considers as reflecting quality of care and on the relative importance of these items for this patient group. Based on the results of this study, the next step will be to develop a test version of this instrument.

References

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Misconcepts about breast cancer in a group of volunteers

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Introduction: Voluntary associations are nowadays called to "make culture", i.e. to bear an accurate message of information, training and professional assistance on the base of international criteria which recognize to the research developed in the field of psycho-oncology the increased capability of the different disciplines in oncology to cooperate the psychological wellbeing of the patient with cancer.

Individuals requested to act in the voluntary institutions in oncology needs therefore to be accompanied and trained in the difficult process which brings to get to a better awareness of their own role and to the acquisition of knowledge and know-how that cannot be left only to the sensitiveness of the single volunteer.

Methods: The lecture will give a feedback of the work made during a 1 year period with a group of about 100 volunteers working in a cancer center to identify misconcepts, false beliefs, wrong information of the participants on breast cancer facts.

Most of the emotional difficulties daily encountered by the volunteers during their contact with the woman with breast cancer are still due to the lack of information about the disease and its optional medical therapies.

Being that the volunteer is not a physician and his role is of course not to substitute the physician, the two psychoterapists conducting the group with a psychosocioanalytical approach could clearly perceive that an important quote of the volunteer anxiety and fear to face women was due to prejudices and the need to get a better understanding of the research developments on breast cancer, together with the characteristics of different treatment options and outcomes.

The objective of the leaders of the group was mainly focussed to sustain and air volunteers' emotions and fears, giving the possibility to express and narrate themselves, their work and their personal way to understand their role as volunteers. Great attention was given to help them to detect and analyse their own controtransferal feelings. Therefore the above emotional dimensions are very much impacted by cognitive aspects and the lecture will demonstrate how the group could get through the whole process of awareness and modification of its behaviours towards the breast cancer patients and could better manage their own feelings.

Conclusions: Misunderstandings, misconcepts, false beliefs are still negatively impacting the way individuals give help in their different professional contexts and roles to women with breast cancer. Institutions could implement the training process of health professionals and volunteers in order to help them to help themselves regarding communication and human relations aspects and consequently better respond to the needs of patients and their families.

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A comparison of clinician and patient symptom reporting during chemotherapy for adjuvant breast cancer: the TACT (Taxotere as Adjuvant ChemoTherapy) trial experience

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Introduction: The TACT trial randomised 4162 early breast cancer pts to FECx4 followed by taxotere x4 (FEC-T) v standard anthracycline regimens of similar duration (FECx8 or epirubicin x4 followed by CMFx4 (E-CMF)). Quality of Life (QL) is a secondary endpoint reported by 829 patients. The present analysis compares clinician and patient reported toxicity during chemotherapy (no comparison by randomised treatment).

Methods: Patients in the QL study rated (not at all, a little, quite a bit, or very much) their experience of 15 toxicities every day during cycles 1, 5, and 8. Clinicians rated patient toxicity at every chemotherapy cycle using common toxicity criteria (CTC). This report compares symptom reporting by: spearman rank correlations between the two responses and frequency of discordance (of 2 or more grades e.g. clinician reports no toxicity patient reports experiencing it quite a bit).

Results: Data from 460, 448, and 406 patients were available for cycles 1, 5, and 8 respectively. There was a highly significant correlation ($p < 0.01$) between clinician and patient reporting of toxicity in all domains with the exception of lack of appetite and mouth ulcers. However, patients generally reported a higher level of toxicity than clinicians. For example, out of 161 patients for whom clinicians regarded as having grade 0 lethargy, 92 (57%) patients regarded themselves to be experiencing tiredness "quite a bit" or "very much". Discordance (of 2 or more grades) between patients and clinicians varied by toxicity, ranging from 1.7% for nail changes to 41.9% for lack of appetite at cycle 1 to 14.8% for nausea & vomiting to 41.1% for pain in muscles/joints at cycle 8. In all domains (except lack of appetite) discordance between patient and clinician reporting increased over time. For example, discordance between diarrhoea reported by clinician and patient was 6.2% at cycle 1, 12.0% at cycle 5 and 14.9% at cycle 8.

Conclusion: There is difficulty in comparing data from these different sources but clinicians and patients are consistent in their assessment of the relative severity of toxicities. However, the CTC grading underestimates patients' reported experience of toxicity. This could be due to patients not disclosing symptoms or clinicians not asking a complete range of questions.

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Does discharge delivered to women following a breast screening assessment clinic appointment, have an equal effect in allaying anxiety when delivered by a Health Professional as opposed to a medically qualified doctor?

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Purpose: There is a significant shortage of Radiologists interested in breast disease in the UK. This study was set up to compare the effectiveness of reassurance on discharge from a breast screening assessment clinic delivered by two different health professionals.

Method: 345 women recalled to assessment were invited to participate in a Randomised Controlled Trial of two groups (control arm – Consultant Radiologists and Interventional arm – Advanced Radiographic Practitioner). Questionnaires collected data on demographics, ethnicity, health values, and current medical conditions. The Hospital Anxiety and Depression Scale was used as the main measurement tool. First questionnaire delivered with recall appointment, second by post with the normal results letter.

Results: 119 women completed both questionnaires (60 to Consultants, 59 to the Advanced Practitioner). Both groups were well matched for age, education and social status. The mean anxiety score for women seen by the Consultants changed from 7.86 to 6.30, a difference of −1.9, and those by the radiographer from 9.06 to 6.62 a difference of −2.34. The results demonstrating no statistical differences between the two groups with the p. values for change in anxiety as. 598, depression. 909, and health values. 627.

Conclusions: Anxiety levels pre and post clinic do not differ from other studies.

Effectiveness of reassurance at discharge does not depend on the designation of the service deliverer.

The diverse nature of our screening population makes it representative of the UK. So this change in service delivery could be equally effective in other units within the UK NHS Breast Screening Program.

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Patient reported outcome (PRO) questionnaires as a qualitative tool in breast reconstruction (BR)

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Introduction: Immediate breast reconstruction is practiced on the basis of its oncologic safety and psychosocial benefits, with lack of evidence for the best method and its assessment. With respect to PROs, the body image scale (BIS) is a key determinant of quality of life (QOL) and cosmetic outcome. This study assesses whether other validated questionnaires for breast cancer, including BIS can evaluate differences in PROs between types of IBR in the context of radiotherapy (RT).

Methods: General and breast cancer specific questionnaires (EORTC (C30 and BR23) and FACT (G and B+4)) will be used together with BIS and hospital anxiety and depression scale with patient self-reporting. None of these are specific for BR. Questionnaires will be evaluated retrospectively (n = 230) patients comprising implant (I)-based Latissimus dorsi (LDI n = 121), Extended LDI (n = 16), sub-pectoral I (n = 57), autogenous ELD (n = 34) and other (n = 2) procedures, to coincide with the anniversary of surgery [median follow-up (FU) of 4 years (range 3 months to 11 years)], with prospective evaluation (50/year) at 3, 6 months and 1 year post BR. Questionnaires will be scored using Likert scales with analysis of all demographic and clinical characteristics. Patient interviews will determine perceived relevance of either EORTC or FACT and identify further BR issues that may be included in a specific BR Quality of Life questionnaire (QLQ).

Results: Since beginning this study, 72 patients have been sent information, with >90% consenting to participate in the study. 53 questionnaires have been completed, with a preliminary analysis of 49 comparing results of LDI (n = 31) to extended procedures (ELDI and ELD, n = 18) and 52 comparing RT (14) or not (38) using SPSS. The mean post-operative FU for LDI was significantly longer (2.81 years) compared to extended procedures (1.24 years) ($P < 0.001$). At this early stage in the study, no statistically significant differences have been shown for any item, subscales or questionnaire relating to type of surgery or RT. Full analysis will be carried out at the end of the study.

Discussion: QOL may improve with time post-operatively and may also be influenced by the type and extent of surgery. It will be important to identify other relevant BR items that are currently not addressed by existing questionnaires. We feel that in order to fully evaluate the effect of BR on QOL, a specifically designed and validated QLQ is needed.

Funded by Iris Garland Trust and Inamed.

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Analysis of the information in the genetic counseling interviews and process

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Introduction: Previous studies have observed how the way the interviews are conducted in the Phase I studies are influencing both the comprehension of the risk and the fears and concerns related to it, together with the level of anxiety of the consultee. Moreover it has been proved that the physicians tends to overestimate the anxieties and the concerns of the consultee. Those aspects should be otherwise present in the area of genetic counseling.

The criticism and the complexity of this theme are pushing us to deep and better know the informative aspects together with the relational dimensions potentially influencing the quality of life of human beings involved in the genetic counseling process, whom positive outcome can contribute to importantly reduce the level of distress and psychic suffering.

Subjects and Methods: In the pilot phase of our study two different self-compilation instruments have been submitted to subjects included in the research group. This group was built up by 50 individuals made of both affected patients and non affected consultees. The two instruments were the STAI State-Trait Anxiety Inventory, in order to evaluate both kind of anxieties (state and trait anxieties) and the Questionnaire for the Evaluation of the Genetic Counseling Interviews, which has been prepared on the base of the theoretical model of Meerwein, which suggests to estimate the quality of the interview taking into account its informative dimension, its affective (emotional) dimension, its interactive dimension. This also wants to focus on some aspects specifically linked to the context (in this case, the identification of a tentative genetic risk.

Respondents were confronted with speeches and encounters developed by two different groups found in cancer genetics, made from different professionals, the oncologist together with the psychologist (for breast cancer) and the oncologist together with the genetist (for the colon cancer) respectively.

Results and Discussion: The preliminary results of those first 50 questionnaires will be presented. These outcomes seems not to reveal any significant differences between the two groups of professionals of the cancer genetics group. In both sub-groups the purpose to increase the consultee's level of information, comprehension and awareness without negatively affect their level of anxiety seems to be met.

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Trait anxiety predicts fatigue in women with early stage breast cancer

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Introduction: Fatigue is a common problem for cancer patients. Most patients undergoing chemotherapy and/or radiotherapy report fatigue. In a study among disease-free cancer patients, severely fatigued patients appeared to score higher on trait anxiety compared with patients who were not severely fatigued (Servaes *et al.*, 2001). We wanted to examine trait anxiety as a predictor of fatigue one, three, and six months after surgical treatment in a prospective longitudinal cohort study.

Method: Every woman who visited the hospital for the first time with a palpable lump in the breast or an abnormality on a mammography and was referred by a general practitioner, was asked to participate in a study on quality of life. Before diagnosis, they completed two personality questionnaires (NEO-FFI, STAI-trait anxiety scale) and at 1, 3, and 6 months after surgical treatment they completed a fatigue questionnaire (FAS) and a quality of life questionnaire (WHOQOL-100) of which only the social support facet was included in the present study. Regression analyses were performed with demographic information in block 1, medical parameters in block 2, social support in block 3, and personality characteristics in block 4.

Results: Between September 2002 and January 2005, 192 women were included in the study. Of them, 87 had breast cancer. Four patients were excluded from the study because they had a locally advanced carcinoma or proven systemic disease. In addition, a number of women did not fully or correctly complete the questionnaires. This resulted in the participation of 69 women with early stage breast cancer.

One month post-surgery 47.8% of the women were fatigued. This increased to 49.2% three months post-operation and than decreased