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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 toxicty 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.