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## Changes of self-concept and body image due to cancer recurrence

K. Münstedt<sup>1</sup>, K. Kirsch<sup>1</sup>, S. Sachsse, W. Milch<sup>2</sup>, M. Zygmunt<sup>1</sup>, U. Lang<sup>1</sup>, H. Vahrson<sup>1</sup>. <sup>1</sup>Department of Gynaecological Oncology; <sup>2</sup>Psychosomatic Medicine of the Universität Giessen, Germany

Purpose: The diagnosis 'cancer' with ensuing cancer surgery, radiotherapy or chemotherapy initiates considerable psychological changes within patients. In this study we compared patients' self-concept and body image in the adjuvant treatment situation to patients' self-concept and body image who had been confronted with cancer recurrence.

Methods: Self-concept and body image of 109 patients with gynaecological malignancy in the adjuvant setting and of 61 patients in the palliative setting (cancer recurrence) were assessed using the "Frankfurter Selbstkonzeptskalen" (FSKN) and "Frankfurter Körperkonzeptskalen" (FKKS).

**Results:** Analysis of variance revealed significant differences (p < 0.05) with respect to either adjuvant or treatment of recurrence in the following subscales favoring patients in adjuvant therapy: irritability by others, firmness against others, state of health, body care and outer appearance, body functioning, fitness of the body. In the scales general fitness, general ability to solve problems, confidence concerning conduct and decisions patients with recurrencies showed higher ratings. Use or non-use of alternative medicine showed differences in the scale esteem by others only.

Conclusion: Being confronted with recurrence of the cancer disease patients show a variety of changes with respect to self-concept and body image indicating that this situation induces greater changes than the initial diagnosis cancer. Some patients' answers seem to reveal personal growth and fulfillment.

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## Long-term physical and psychological sequelae in patients treated with high-dose chemotherapy with peripheral stem cell rescue

R. Cajal, A. Calvo, J.I. Mayordomo, D. Isla, M. Alonso, A. Yubero, J. Herráez, A. Sáenz, A. Lobo, A. Tres. Medical Oncology & Psichiatry Divs. Hospital Clínico Univers, Zaragoza, Spain

Rationale: There is little information on the long-term physical and psychological sequelae of high-dose chemotherapy with stem cell rescue (HD-CHT), a novel aggressive therapeutic options for patients (pts) with lymphoma and chemosensitive solid tumors (mostly breast cancer).

Methods: The prevalence of psychological morbidity was evaluated through Goldberg's General Health Questionnaire (GHQ) (previously validated in Spanish by us. (Lobo et al., Psycholog Medicine 16, 135, 1986) in 18 consecutive pits treated with HD-CHT in our institution (Feb 1995—Feb 1996). Age: 21–62 years. Sex (male/female): 5/13. Tumor types were breast cancer (12), non-Hodgkin's tymphoma (3), germ-cell cancer (2) and Ewing's sarcoma (1). Physical sequelae were also evaluated. GHQ was administered 1 year after HD-CHT. To maximize specificity, cut-off was 6–7.

Results: Only 6 of the 18 pts (33%) scored 6 or higher. Disease status influenced scoring: 2 of 13 pts (15%) in complete response scored 6 or higher as compared to 4 of 5 (80%) with relapse. Scale B (anxiety) had the highest scores and scale D (depression) the lowest. The prevalence of psychological morbidity found (33%) is not higher that previously reported for hospitalized oncological pts (40%). No significant renal, cardiac or lung sequelae were found, except for 1 pt treated with high-dose BCNU who has restrictive lung disease by spirometry, with minimal physical limitation. Performance status (ECOG) in pts without relapse: 0 (12 pts); 1 (1 pt).

Conclusions: These results, derived from a small patient series, suggest that in spite of having undergone aggressive HD-CHT, patients surviving 1 year have few physical sequelae and very adequate psychosocial adaptation.

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#### Neoplastic patients and awareness of the diagnosis

M. Destefanis, A. DallaMola, F. Castiglione, <u>G. Porcile</u>. Osp. S. Lazzaro, Alba. Italy

The degree of awareness of the diagnosis in italian neoplastic patients (pts) is usually low. To assess this degree in our pts, we purposed a questionnaire with 11 items to 168 consecutive pts. 64 were males, 104 females; median age was 61.4 ys. 78 pts had advanced disease, 90 were free of disease. Pts conscious of their own malignancy were defined "well-informed". Clinical

and sociocultural features were detected in well-informed and not-informed pts. Data are summarized as follows.

Patients		Se	X	Educat, level			Site of disease		
	#	m	ī	low	med	hi	breast	g.i.	lung
Well-informed	71	15	56	38	16	17	41	14	5
Not-informed	97	49	48	82	12	3	28	29	16
		p < 0.001		p < 0.001			p < 0.001		

Our data confirm an unsatisfactory awareness of their own diagnosis in our series; however 131 pts stated that, in case of neoplasia, they would like to be fully informed. In our study the awareness of diagnosis is not influenced by stage of disease. Data collected in the table describe a particular subset of well-informed pts: the well-informed patient is often a woman, fifty years old, affected by breast cancer, with a good educational level.

The degree of awareness in our pts is lower than other reports from anglosaxon countries; the reasons can be identified in psychosocial factors as the life in a rural area, where we act, and a low educational level. In order to improve patient's information and optimize our clinical practice we think that our medical and nursing staff must find different approaches to different subsets of patients.

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## A new doctor-patient information link: The "triple brochure" project as a model

A. Gaisser, K.-D. Humbert. Cancer Information Service, Deutsches Krebsforschungszentrum, Heidelberg, Germany

A satisfactory doctor-patient relationship strongly depends on the quality of communication about the disease, especially in case of chronic illnesses such as cancer. Even if the doctor is the patients' preferred source of information they make use of many other sources. "Public" information, though, never applies to an individual case, making it necessary that the patient discusses it with their doctor for explanation and individual applicability. This requires a common information basis and the doctor's acceptance of the patient's information source as valuable and reliable. Based on an assessment of a variety of brochures and a survey of cancer patients questioned on their needs and expectations, the "trias brochure" project aims at fulfilling these requirements: The components are a comprehensible and comprehensive patient brochure on all current standard and experimental options of cancer treatment and support, a corresponding brochure for doctors with scientific and psychooncological background information and, supplementing the patient brochure, a third brochure about the patient's specific type of cancer. All three brochures are written by experts in the field of cancer information and cancer care in close cooperation, thus assuring consistency. This kind of "triple brochure" is expected to be a useful tool in establishing and keeping up a trusting doctor-patient relationship and efficient communication that meets the patient's needs and could as a model be applied to other diseases. The brochures are widely distributed to practitioners to be handed out to the patient personally. This is to emphasize that they are part of the doctor's care for the patient and means that he will respond to all arising questions. Details on the project and first results of an evaluation will be presented.

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# Cancer in the elderly – Are there different needs for information? An evaluation of calls to the German cancer information service

S. Wilcke, H. Stamatiadis-Smith. KID, Deutsches Krebsforschungszentrum Heidelberg, Germany

Since 1986, KID, the German Cancer Information Service, has answered almost 120,000 calls, giving up-to-date scientifically based information on cancer-related topics to the public. The service is financed by the German Federal Ministry of Health and the Ministry of Social and Health Affairs of Baden-Würthemberg. Inquiries are statistically evaluated on the basis of a call record form. Evaluation may also be used to identify areas of specific needs.

Cancer in the elderly, now a majority in the European Union compared to patients below 60, has been attracting more clinical attention only recently. Therefore, it may be useful to learn about the needs for information in this age group. Samples of KID-callers from the period 1992–1996 are analyzed in order to find age-specific needs and interests.

The number of callers is small compared to the incidence rate in the older

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ana group Interest

age group. Interests differ with changing frequencies in cancer localization, for instance as prostate cancer becomes more frequent an increasing number of elderly men are calling KID. Methods of diagnosis are more often asked by the elderly. In both age groups unproven methods are at the top of all questions concerning therapeutical aspects. There is an increased wish for just talking to someone on the telephone among the elderly compared with other groups of callers. On the other hand, average length of calls do not differ between age groups.

Cancer care providers should take into account that in addition to similar needs for information that all age groups have in common the elderly have age-specific needs which have to be considered.

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#### Toward a theory of loss in women with breast cancer

M. Barton Burke. College of Nursing, University of Rhode Island, Kingston, RI, USA

Loss and grief are concepts that health care professionals deal with regularly. To date explication of the concept of loss in the literature has not been seen due to the continual linkage with the parallel concept of grief. Current understanding of loss is tied to grief. People diagnosed with cancer experience loss, losses, or the threat of loss as a result of diagnosis, treatment, or impending death. Breast cancer is one cancer in which loss can be observed both implicitly and explicitly. Since breast cancer affects females of all adult age groups and its incidence is on the rise, an understanding of the feelings and responses of these women is preliminary to compassionate caregiving by the professional.

Four women with breast cancer were intensely interviewed over a four month period of time to uncover their perceptions of loss. The hybrid model of concept development was utilized as the method for merging theoretical findings with empirical evidence. As with most preliminary work, findings centered around the process of discovery and were qualitative in nature. A definition of loss was developed; additional findings from this study include characteristics of loss, common themes related to loss, and a trajectory of loss which offers an alternative to current thinking about loss and the connection to grief. There appears to be an enduring quality to loss which can be described years after the loss event. This presentation highlights preliminary findings which suggest a theory of loss for women with breast cancer.

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### How to tell cancer patients – A contribution to a theory of diagnosis-communication

P. Salander, A.T. Bergenheim, P. Bergström, R. Henriksson. Department of Oncology and Neurosurgery, Umeå University, Sweden

Purpose: "How to tell cancer patients" is an important question in cancer care. It provokes distress in physicians, and a failure in relating diagnosis may cause an arrest in the patient's process of coping with anxiety and a reduction in subjective well-being.

Methods: This contribution to a theory of diagnosis-communication is empirically based on an earlier interview study of patients with malignant brain tumours, and theoretically based on contemporary object-relational psychoanalysis.

Results: It is proposed that a beneficial doctor-patient encounter may be seen as characterized by the acknowledgement of the doctor 1) as an unconscious protection against death and 2) as a facilitating environment for the patients reconstructive process.

Conclusions: It may be proposed that the awareness of the transference from the child-parent to the patient-doctor relationship enables introspection as a means to improve skilfulness in "How to tell". Introspection may thus provide us with guiding knowledge grounded in ourselves.

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#### Cancer patient information and support

<u>Leena Keskinen</u>, Eija Salmi, Klaus Lehtinen, Ulla-Sisko Lehto-Jämstedt, Kirsti Taskinen, Pirkko Kellokumpu-Lehtinen. *Department of Oncology, Tampere University Hospital, Finland* 

Purpose: To increase the quality of care, information, and support cancer patients (pts) receive, we studied their satisfaction of the care they had received from the health care system and the clinic of oncology.

Methods: 325 pts filled the questionnaire with 36 items in February 1996.

Results: 74% had their cancer diagnosis (dg) confirmed in one month after the first medical examination. 50% experienced the time to be too long. Of the 91 that expressed an opinion on the reasonable time to wait for dg, 56% considered one week to be reasonable, only 2% were willing to wait for a month.

The doctor told the dg to 57% in private, additional staff or pts were present in 24%. The rest were informed by a letter or by phone. Only 18% were unsatisfied in the way the dg was told. 70% were not told how to get additional information.

76% had received information from a doctor, 44% from a nurse. 25% had felt an unmet need for help before the treatment at the oncology clinic started.

79% were satisfied in the services of the doctors and 76% in those of the nurses in the clinic of oncology. The most frequently mentioned reasons for satisfaction were high quality of care, the positive attitude and time the staff had for pts. Patient's social status had no correlation with any of the variables.

Conclusion: In spite of advises to inform the patient on the diagnosis in a calm situation and in private, this is true only in half of the situations. In general only 25% were dissatisfied with the services of the clinic of oncology.

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## Radiotherapy-induced changes of psychological health in patients after breast conserving surgery

A.N. Rahn, S. Mose, A. Zander-Heinz, K. Budischewski, S.B. Bormeth, F. Saran, Ch. Thilmann, I.A. Adamietz, H.D. Böttcher. Department of Radiotherapy, University Hospital Frankfurt, FRG

Purpose: There is only few information about the influence of postoperative irradiation on the psychological health of breast cancer patients. Purpose of this study was the evaluation of the psychological burden of these patients and changes in psychological health during radiotherapy (RT).

Patients and Methods: Between 10/95-4/96 postoperative  $\pm$  adjuvant systemic therapy was applicated in 53 breast cancer patients (age 31-76) after breast conserving surgery. In the beginning and at the end of radiotherapy they answered a questionnaire asking for coping strategies, psychological distress, side effects and influence of surroundings.

Results: 92% stated to be well informed about radiotherapy. 83% tried to obtain further information about RT. 56% repress thoughts about radiotherapy and 81% tried to distract themselves. Talking with the physician (94%) or the partner (84%) was perceived as helpful. 40% were anxious about RT and possible side effects (54%). At the end of therapy anxiety was reduced: 77% of the patients stated to be anxious only initially or never, only 19% were anxious always or most of the time. 38% of the women reported emotional distress induced by the fact of being irradiated. All patients stated that contact to the medical staff made it easier to stand the treatment.

Conclusions: Radiotherapy is experienced more positive than initially expected by the patients: The relation between patients and medical staff plays an important part in the reduction of irradiation-related psychological distress.

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### Quality of life in patients with advanced NSCLC: Evaluation of a neoadjuvant combined modality treatment

A. Schumacher<sup>1</sup>, D. Riesenbeck<sup>2</sup>, Ch. Rübe<sup>2</sup>, M. Thomas<sup>1</sup>, J. van de Loo<sup>1</sup>, N. Willich<sup>2</sup>. <sup>1</sup>Dept. of Internal Medicine Hematology/Oncology; <sup>2</sup>Dept. of Radiooncology, University of Münster, FRG

Purpose: Intensive combined modality treatment for NSCLC Stage III aims to improve longterm prognosis of patients. As such therapy might be associated with high morbidity, quality of life (QL) is an important parameter to be assessed.

Methods: Patients with NSCLC Stage III are treated in a randomized multicenter trial: After 3 courses of Cisplatin/Etoposid (CE), patients receive either standard treatment of surgical resection and conventional radiotherapy versus hyperfractional irradiation combined with chemotherapy (Carboplatin/Vindesine) before surgical resection. QL is being analysed throughout therapy, evaluating defined specific parameters by the EORTC-QLQ C 30 and the appropriate lung cancer module.

Results: Currently, 45 patients are enrolled in the protocol and 31 are evaluable after the first 6 months of therapy. Before treatment, patients assess their Physical (mean: 85.3) and Cognitive Functioning (86.6) as relatively good, their Emotional (65.3), Role (68.2) and Social Functioning (69.4) as well as Global Health Status and Subjective QL (55.6) as