1202

THE PSYCHOLOGICAL ACCEPTABILITY OF FOLLOW UP IN A GROUP OF SARCOMA PATIENTS

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The need for a more or less intensive follow up of the asymptomatic cancer patient in complete remission after treatment is a matter of debate. A minimalist policy is opposed to a maximalist one. Both economical and psychological concerns are entailed, while the clinical effectiveness is doubtful. We have been trying to assess if intensive follow up causes psychological distress to the patient.

From September 1991, 30 patients with soft tissue sarcoma in complete remission at 6 months to 2 years after completing their treatment were given a short questionnaire on their experience with follow up visits. A personality test, *16 P.F. Questionnaire*, was given too. These patients were submitted to a chest X ray and a clinical exam every 2-3 months.

Twenty-four patients reported as "positive" their experience of the follow up visit ("very positive" in 15 cases), and 21 were "satisfied" with the current schedule. "Anxiety" was experienced for 1 to 30 days before the scheduled visit (median: 7 days). The good outcome of the visit allowed these patients to feel reassured for one or more months. The personality test did not show these patients to deviate significantly from the average and so personality factors are unlikely to have affected the answers.

These are preliminary results of an ongoing study. We conclude that psychological investigation of patients' experience with follow up is needed. Follow up visits are not necessarily distressing and sometimes the patient may actually need for them on a regular basis. Psychological factors should be considered when assessing follow up policies.

1204

HOPES AND EXPECTATIONS OF SWEDISH CANCER PATIENTS: CONTRADICTIONS SURROUNDING SATISFACTION WITH CARE

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This paper will present a study of hopes and expectations concerning the professional health care sector, as expressed by a group of Swedish cancer patients. The data is derived from a cross-sectional study of patients diagnosed with a malignant disease at one general hospital in Stockholm in 1987. Semi-structured interviews using both pre-coded and open questions were conducted with 46 patients, concerning the individual's perceptions of care received and problems experienced.

When conducting the interviews, we were initially perplexed by the seeming discrepancy between the problematic situations and experiences described in narrative form by the participants, and the high rate of positive responses to direct questions concerned with satisfaction with care. By combining quantitative and qualitative data, and using a process of analysis inspired by medical anthropology, a means of understanding what satisfaction with care represents in this context has been obtained.

Patients appear to organize their experiences in a manner which 'works'. General dissatisfaction with care may not be an effective technique for promoting well-being when diagnosed with a potentially life-threatening disease. The patients in this study avoid dissatisfaction in a number of ways, which include assuming responsibility themselves, accepting the unarticulated as a form of discourse, and adapting frameworks for that which is 'normal' from the professional sector.

1203

BURNOUT SYNDROME AMONG SPANISH ONCOLOGISTS

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In order to assess the incidence and importance of the "burnout" syndrome among Spanish oncologists, we developed a questionnaire with 8 items.

MATERIAL AND METHODS. The first four questions asked to what degree the physician was affected by 1) the high mortality rate of cancer patients, 2) the fact that family frequently distrusts physicians, 3) overwork and 4) problems in the medical team (nothing, a few, much, very much, and a proposal for improvement). Other questions asked if the doctor felt very burnout (scale from 1 to 5), description of this feeling (frustration, disinterest, boring, depression or failure), if the profession had fulfilled his/her expectatives and if the participation in clinical trials could ameliorate that feeling. The questionnaire was distributed among 250 oncologists.

RESULTS. Forty-nine oncologists answered the questionnaire (20%). The mean time they had been working as oncologists was 13 years. The high mortality rate of cancer patients affected "much" to 26 doctors (53%) and "a few" to 15 (30%). Family's distrust affected "a few" (20 cases, 41%) or "much" (21 cases, 43%). Twenty-two doctors (45%) answered "very much" to the question about overwork, followed by 20 (41%) who answered "much". Problems in the medical team affected "much" to 26 doctors (53%) and "very much" to 18 (37%). In the scale about the degree of burnout, the most frequent value was "2" (21 cases, 43%), followed by "3" and "4" (10 cases each, 20%). Frustration better defined this feeling. Thirty-six doctors (73%) thought that the specialty had fulfilled their expectatives, while 35 (71%) asserted that clinical trials could be of benefit in this setting.

CONCLUSION. The incidence of the burn-out syndrome among the Spanish oncologists seems to be low, although many aspects exist that could be improved.

1205

"ON LINE" COLLECTION QUALITY OF LIFE (QL) ITEMS IN THE ONCOLOGICAL HOSPITAL AT HOME (OHH): A NEW APPROACH

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Information about patient's (pts)experiences of far advanced cancer disease and treatments are not routinelly collected on a large scale in clinical research and medical practice. From 1985 ANT has provided an Hospital-at-home care program for advanced and very advanced cancer pts, and during 1992 a total of 2407 pts were treated in five differents Italian areas by a team of oncologists, nurses and psycologists working round-the-clock. Since March, 1992 a "on line" computerized data collection regarding some QL items has been performed in the ANT OHH of Bologna. Each pt received a regular weekly evaluation regarding 1) subjective status (symptoms and pain control, side effects of the treatments); 2) Functional status (self-care performance, nutritional conditions, sleeping and cognitive functions); 3) Psyco-existential status (disease coping, emotional functioning, life feeling). Based on weekly score, each investigated area is monthly scored from 1 to 4, with a summated maximum possible score of twelve. About 1460 pts were evaluated during 1992, with a 3.2 month of mean follow up. The most important problems were pain (54%) and anorexia(40%) . Morphine was employed in 16% , cortisonics in 31%, anabolic drugs in 29%, and psycotropic drugs in 50% of the pts. The "on line" computerized data collection regarding QL items is in our experience feasible on large scale and can really improuve the "quality of care" of the OHH.