323

Children's reactions to parents with cancer

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Purpose: A prospective study to investigate children's adjustment to a parent's illness during and after diagnosis and treatment: to consider the link between the adjustment of the child and parent and: to assess level of support and needs of the family.

Methods: Semi-structured interviews are combined with standardised self-report measures. Data is collected from parent, child and school teacher at one year and at two years post diagnosis from a sample of 100 patients who have dependent children aged from 8–16 years.

Preliminary Results: From the interview data, descriptive accounts of children's positive and negative reactions during the first year of the parent's illness will be presented. The interview data highlights the potential role of both the school and the hospital regarding family adjustment.

Conclusion: Factors which could promote risk or resilience for children of cancer patients will be clarified next year, when the data set is complete.

324

Caregiver burden among partners of cancer patients

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Purpose: Cancer is assumed to create a stressful situation not only for the patient but also for the primary caregiver. Caregiving may be perceived as a burden, or conversely as a challenge. Caregiver responses were evaluated among 78 partners of newly diagnosed colo-rectal cancer patients who have been undergoing surgery.

Methods: It is widely recognized that a multi- dimensional approach is needed to characterize burden associated with caregiving. In this study, the Caregiver Reaction Assessment Scale (CRA) was used to examine negative as well as positive responses to giving care.

Results: Five dimensions of caregiver reactions were identified: impact of caregiving on health, finance, family support, daily schedules and self-esteem. Preliminary findings indicated that female caregivers tend to feel a stronger negative impact on their health. Low socio-economic status was significantly related to a higher impact on finance. Giving care to the patient was associated with an increased impact on daily schedule, regardless of the type of care. Furthermore, giving personal care also had an impact on partners' health, suggesting that this type of care is most burdensome. Caregiving related self-esteem increased over time, which may indicate the caregiver's adaptation to his/her situation.

Conclusion: These findings stress the importance of viewing the partner caregiver's reactions from a multi-dimensional perspective and they might contribute to the development of interventions aimed at reducing negative reactions to caregiving.

325

Preventing affective disorder amongst partners of cancer patients

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Purpose: A problem-solving intervention is currently being offered to the partners of patients who have been referred to the psychiatric service and are diagnosed as having a major depressive or generalised anxiety disorder. The aim is to prevent the development of affective disorder amongst the partners.

Methods: 300 partners recruited to the study are being randomised to the intervention or control group and the two arms of the study are stratified for factors known to be associated with affective disorder. Partners who are randomised to receive intervention are offered a maximum of six intervention sessions with a social worker or a psychiatric registrar. The first session is an assessment in which the partner reviews his/her experience of the illness and identifies current difficulties. Future sessions are planned on the basis of this assessment.

The intervention focuses on current concerns and coping deficits. Particular attention is given to communication problems, whether with medical staff, with the patient, or with other confidants.

The intervention will be described and interim findings reported and discussed.

326

Does your personality effect how you communicate with cancer patients?

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Purpose: Good communication skills are a vital part of cancer care. It is generally accepted that education and training helps improve communication skills but there is little knowledge of why some people improve more than others. Many suggestions have been put forward including personality but there is a dearth of research investigating this. A study was set up to investigate whether a nurse's personality is related to how they communicate.

Method: Fifty registered nurses undertaking a 26 hours communication training programme were invited to participate in the study.

Each nurse, before commencing the course, completed: a self report demographic questionnaire, an audio-taped nursing assessment and the sixteen Personality (16PF) questionnaire. Three months post-course each nurse completed an audio-taped nursing assessment. The audio-tapes were rated by 2 raters who had been used in several studies and tested for reliability and validity. The data were analysed using SPSSX. Statistical tests included Mann-Whitney U Test, Wilcoxon Matched Pairs Signed Ranks test and Spearman correlation co-efficient.

Results: Fifty nurses (100%) participated in the study. Preliminary results (analysis is ongoing) indicate that, in line with a previous study of breast care nurses (Tait 1994), the nurses personality profiles suggested that they were genuine and warm in their relationships with others. Those who were social, bold, adventurous and willing to accept a challenge showed the greatest improvements.

Conclusion: Preliminary conclusions indicate how nurses communicate could be related to their personality.

327

Patients preferences for involvement in treatment decisions in palliative cancer care

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Purpose: The aim of this study was to evaluate the extent to which hospitalized patients with cancer and a palliative treatment goal wanted to be involved in decisions regarding their treatment.

Methods: Patients' preference for involvement in treatment decisions was evaluated using a self-administered questionnaire (categories: active, collaborative, or passive role). Fifty-nine patients with advanced cancer and a palliative treatment goal were compared to eighty-six patients with chronic non-neoplastic disease and one hundred fifteen non-hospitalized persons.

Results: Mean age for the patients with cancer was 58.6 years, for the patients with chronic non-neoplastic disease 58.2 years, and for the non-hospitalized persons 47.9 years. Only 9% of the patients with cancer wanted to play an active role in the decision making process whereas 73% preferred a collaborative role together with the physician, and 18% preferred a passive role. In comparison, 17% of the patients with non-neoplastic disease wanted to decide actively, 49% in a collaborative, and 34% in a passive way. The respective numbers of the non-hospitalized persons were 40%, 56%, and 4% (p-value = 0.001 for group difference after age stratification). Younger age, higher education, employment status and a higher Karnofsky index were significantly associated with the preference for an active role.

Conclusion: Most patients with advanced cancer want to participate in a decision regarding their treatment.

328

The challenge of informed consent

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Purpose: Informed consent (IC) is the basic requirement for any diagnostic or therapeutic treatment. Consent is valid if the patient was adaequatly informed and could freely decide. It seems important to evaluate the quality of current information practice.

Methods: Pts undergoing bronchoscopy were investigated by standardized interviews about contents and circumstances of the information they got before they gave IC. Furthermore they were asked whether they would like more or rather less information and they were tested with the State-Trait-Anxiety-Inventory. Between Jul 94 and Feb 95 we evaluated 80 pts.

Results: Generally the legal requirements were met, although out of administrative reasons some pts were informed shortly before the bronchoscopy. 77 pts (96%) were satisfied with the information given and only 3 pts would have wanted more. However, 33 pts (41%) could not remember one single of nine mentioned risks of the procedure and 19 pts (24%) did not even remember that they were not allowed to eat and drink shortly after the investigation. Additional information with a video was perceived as informative but inducing anxiety.

Conclusion: Informing patients about medical procedures is a complex communicative challenge. We suggest that valid IC requires to prove that the information given actually reached the patient.

329

Evidence of work-induced stress among oncology clinical and non-clinical health care personnel in Glasgow and the West of Scotland

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Purpose: Many members of health care staff are in daily contact with anxious and/or depressed and despairing patients/relatives. Such frequent interactions can lead to misunderstanding, role ambiguity and feelings of inadequacy and failure. Total breakdown through burnout and enforced absence from duties may well ensue. The need to identify and quantify such effect, is being attempted in a sample of clinical and non-clinical health care personnel working in Glasgow and the West of Scotland.

Methods: A self-report method has been adopted, using the Maslach Burnout Inventory, the Eysenck Personality Questionnaire and an 'in-house' questionnaire, designed to elicit data on work-related, self-perceived psychologic, intrapsychic and interpersonal demands and needs.

Results: These to date, show some evidence of on the one hand, high positive correlation between for example, poor job satisfaction, workload pressure, feelings of being undervalued, low self-rating of competence in dealing with patients'/relatives' problems and on the other, emotional exhaustion, depersonalization and impaired personal accomplishment.

Conclusions: "Care for the care givers" constitutes an urgent service need. These and other data to be reported, have important particular and general implications for the QL and overall efficacy of health care staff, as well as for their continuing optimal fulfilment of role and delivery of service.

330

The role of child life intervention in pediatric radiation oncology

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Purpose: A pilot program utilizing a child life specialist in the radiation oncology department was designed in response to the increased use of conformal techniques which require greater precision and longer treatment times. A preparation program was designed to ensure patient cooperation and decrease the need for daily anesthesia in young patients.

Methods: The preparation program included: 1) Assessment of the needs of each child. 2) Introduction of the child to the radiation therapy (RT) procedures by familiarizing the child with equipment, staff, environment 3) Achieving motion control using individualized techniques. The intention of this design was to promote a high degree of cooperation with a focus on children between the ages or 3 and 6 because this age group has traditionally required anesthesia.

Results: Between 3/96–1/97 the JCRT has treated 96 pediatric patients. Of these 96 children, 34 children were between ages of 3 and 6 years old. 85% of the children completed their RT without the need for anesthesia.

Conclusion: We found that a child life program within a pediatric radiation oncology practice will decrease the need for anesthesia in patients age 3 to 6 years old and this intervention decreased the overall treatment time for the patients and increased the efficiency of the department. The multi-disciplinary team approach and the quality of life benefits to the patients and their families will be discussed.