1274 POSTER

The Swedish Cancer Society's helpline - a complement to the health care system. The satisfaction of patients and relatives/friends

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Introduction: Since 1994, The Swedish Cancer Society offers patients with cancer, relatives/friends and others, cancer information and psychosocial support through a telephone helpline.

Aim: To study the reasons for cancer patients and relatives/friends to call and their perceived satisfaction with the Swedish Cancer Society's helpline.

Method: A study specific questionnaire was developed and used. It included 20 questions, 13 were in the form of a four-point category scale and seven were open-ended questions. The questions concerned satisfaction with received information and psychosocial support. All patients and relatives/friends who called the helpline during two and a half months were asked to answer the questionnaire. A total of 392 persons completed the form (61% response rate) of which 50% were patients and 50% were relatives/friends. The group of relatives/friends consisted of more women, were younger and had a higher level of education compared to the group of patients.

Result: The results showed that the patients and relatives/friends were very satisfied with the contact with the helpline of the Swedish Cancer Society. No differences were found between the two groups or between men and women. The participants were especially satisfied with the psychosocial support received from the staff and their competence. To be given enough time for the conversation was also appreciated. Information about cancer, its treatment and care were the main reasons for calling the helpline. More relatives/friends than patients called to receive psychosocial support. Another reason for calling the helpline was dissatisfaction with the health care system in Sweden.

Only a few persons were discontent with something in the contact with the helpline. Suggestions of improvement were e.g. increased accessibility of the helpline and in depth information about a certain cancer disease and its treatment. There was also a request of increased marketing of the helpline's existence.

Conclusion: This study confirms that the helpline is a valuable complementary to the Swedish health care system for patients with cancer and their relatives/friends regarding information about cancer and psychosocial support.

1275 POSTER

The cancer information centre, does it work?

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The NHS Cancer Information Strategy (DOH 2000)recognises the importance of information walk-in centres as part of a comprehensive approach to information provision. CancerBACUP is the UK's leading cancer information charity. In 1998, CancerBACUP joined forces with Nottingham City Hospital Trust to create a walk-in cancer information centre. Five years on, the centre is flourishing and has dealt with enquiries from more than 7000 people affected by cancer. The Nottingham City Hospital Trust (NCHT)is a large teaching hospital with 1100 beds, incorporating a regional cancer centre. The CancerBACUP centre offers access to high quality information booklets and factsheets. More importantly, a cancer information nurse specialist gives individual attention to anyone requiring information, support and advice on any aspect of cancer. By complementing the cancer services offered at NCHT, the service is now regarded as integral to comprehensive patient/relative care. The multi-professional cancer team appreciates the resources of the CancerBACUP centre and has confidence in the professionalism of its staff. Extensive CancerBACUP resources including an in-house database, library and research department enable the Nottingham centre CancerBACUP nurses to achieve a high standard of patient care. As part of a comprehensive professional programme, the nurse is also required to take part in reading and critiquing research articles, conferences, study days, in-house training and has regular clinical supervision. As well as patients and carers, health professionals benefit from the centre nurse's expertise in information provision. The CancerBACUP nurses have unique skills and knowledge. They are regularly asked to speak on medical and nursing courses run by Nottingham University and to macmillan nurses, local hospices and cancer support groups. Staff from CancerBACUP and NCHT meet regularly to discuss the strategic development of the service. This dynamic relationship is crucial to providing an effective user-focused service. The CancerBACUP walk-in centre is undoubtly a success story. It has been of mutual benefit to all parties. For NCHT it has provided access to high quality information and support for patients and their relatives. CancerBACUP has since developed other partnerships and opened six more walk-in centres around the UK.

1276 POSTER

Improving patient access to health care professionals: a pilot study evaluating the usefulness of e-mail communication with patients with lung cancer

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Being able to access expert information and advice promptly, in times of need and in between scheduled appointments, is an important aspect of care for patients with lung cancer (National Cancer Alliance 1996, Corner et al 2000). It is particularly important for patients with lung cancer who experience a multitude of difficult symptoms and complex psychosocial concerns, often with little help from health care professionals (Hopwood & Stevens 1995, Krishnasamy & Wilkie 1999, Hopwood & Stevens 2000)).

At a recent European School of Oncology Masterclass in Clinical Oncology in Montecatini, Italy in August 2002, the audience were challenged to consider using e-mail to communicate with patients and caregivers in an attempt to improve patient access to non-urgent information and advice.

This poster will describe an ongoing pilot project undertaken by lung cancer nurse specialists at a cancer centre in the United Kingdom to evaluate the usefulness of offering patients with lung cancer and their caregivers e-mail access to nurse specialists. This poster will describe the project in detail and discuss the findings to date. Implications for practice and futher research will also be discussed

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1277 POSTER

Chemotherapy induced nausea and vomiting (CINV) in routine practice in Spain: assessing incidence and impact on patient's daily life

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Background: Chemotherapy-induced nausea and vomiting (CINV) remains a distressing side effect of anticancer therapy for many. If not adequately controlled, CINV may interfere with a patient's ability to carry out daily activities as well as with the delivery of cancer treatments.

Objective: To assess the incidence and impact of CINV on daily life activities in patients receiving moderately to highly emetogenic, first-cycle chemotherapy (CTx), in routine practice, in Barcelona, Spain.

Methods: The incidence of CINV was evaluated from patients' self-reported diaries for the first five days following CTx. Patients reported the number of emetic episodes they experienced as well as the types and amounts of antiemetic drugs taken prior to chemotherapy. Daily nausea ratings were recorded on a 100-mm visual analogue scale (VAS) prior chemotherapy (baseline) and post chemotherapy, days 1-5 (CTx is given on day 1). VAS score differences were calculated between baseline and each of days 1-5. A VAS score of <5 mm was defined as having no nausea. The impact of CINV on patients' daily life was determined using the Functional Living Index for Emesis (FLIE), a validated nausea-and-vomiting-specific outcome measure completed by patients on day 6. No impact on daily life was defined as an average item score > 6 on the 7-point scale.

Results: 104 patients, 65 (63%) female and 39 (37%) male, were enrolled from the Catalan Institute of Oncology, Barcelona, Spain. Average age 54; breast cancer 43%; lung cancer 34%; ovarian and other cancers 23%. CTx included: doxorubicin (41%), cisplatin (37%), vinorelbine (24%), carboplatin (20%), cyclophosphamide (14%), and fluorouracil (5FU), 13%. Antiemetics drugs were administered to all patients: dexamethasone 99%; metoclopramide 63%; and 5HT3, 99%. 32 (31%) patients suffered from acute nausea (Day 1) with mean VAS score difference 13.21mm (95%CI: 8.48-17.94). Delayed nausea was observed on Days 2-5, peaking on day 3 with 39 (38%) patients registering a mean VAS score difference of 13.68mm (95%CI: 8.96-18.40mm; figure 1). 51 (50%) patients reported emetic episodes (12% acute and 48% delayed). 75% of patients with nausea and 51% with emesis reported a significant impact on their daily life, hampering their ability to carry out activities of daily living comfortably.

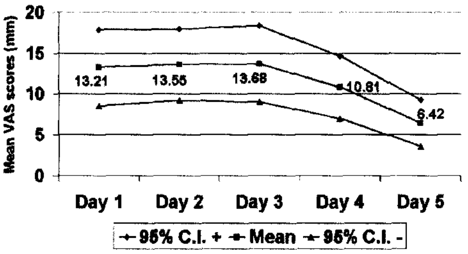

Fig. 1. Nausea Visual Analog Scale: Mean VAS score differences & 95% C.I.

Conclusion: Despite receiving prophylactic antiemetic therapy, a high proportion of patients undergoing chemotherapy still experience acute and delayed CINV with subsequent negative impact on their daily life.

1278 POSTER

Palliative consultation team: functions in a university hospital

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Palliative care improves the quality of life of patients and their families when faced with problems of life-threatening illnesses. In Iceland, a society of 290 000 inhabitants, the movement of specialized palliative and hospice care has grown significantly over the past 20 years. Currently, there are three free standing home care hospice units, two hospital palliative inpatient units and one palliative care team. Clearly palliative care may be provided in a variety of settings which calls for planning and coordination of services and access to specialized services such as a consultation team.

The palliative care team at Landspitalinn University Hospital in Iceland (1000 beds) was established in 1997 following a study among hospital staff showing the need for the type of services a multidisciplinary palliative team could offer.

The main overall goal of the team is to improve palliative care by consulting and supporting hospital staff, patients and their relatives when dealing with life-threatening and terminal situations; and by formal and informal teaching as well as research.The team is led by a nurse and consists of a part-time palliative care physician, geriatric physician, social worker, priest and two full-time nurses.

Since 1997 the activity of the team has increased significantly. The number of requests have increased from 36 in 1997 to 274 in 2002, and the number of visitations have increased from 284 to 1405 respectively. In 2002 the mean number of daily visitations was 5.5. Most team visitations are made by the nurses (> 80%). Most requests are from oncology and surgical wards and the main reasons are discharge planning, support to patient and family, and symptom managament. The majority of patients are diagnosed with a cancer (87%), aged 70-80 and slightly more women than men.

The palliative care team has an important role in a acute university hospital in relation to advancing clinical practice for palliative care patients and their families and in relation to teaching and research. A further description of the team's activity will be provided.

1279 POSTER

Posttraumatic stress disorder in parents of children with cancer and benign brain tumours

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Background: Learning that one's child has a life-threatening disease has been introduced in DSM-IV as a qualifying event for posttraumatic stress disorder (PTSD). The aim is to prospectively assess (1) presence of PTSD in parents of children with cancer and benign brain tumours, and (2) whether, and if so, to what extent (a) parents' experiences of emotional support, perceptions of the child's experiences of illness related distress, satisfaction with care, and (b) medical factors related to the child's disease and treatment explain the presence of PTSD in parents.

Methods: A longitudinal design with six assessments: one week after the child's diagnosis (1), two (2) and four (3) months after diagnosis, one week after the last treatment (children treated with chemotherapy)/six months after diagnosis (children with brain tumours, not treated with chemotherapy or radiation) (4), three (5) and twelve (6) months after the last treatment/six months after diagnosis. All parents of newly diagnosed children at four out of six paediatric oncology centres in Sweden will, during 12 months at one hospital and 18 months at three hospitals, be asked to participate. Inclusion started in April 2002 and approximately 340 parents of 170 children will be asked to participate until September 2003. Data are collected by structured telephone interviews using the questionnaires PCL-C, experience of emotional support (some of us, newly constructed questions), MSAS 10-18, and a modified version of CASC SF 4.0. Medical data will be collected from the children's medical records.

Results: In March 2003 234 parents, of 113 children, were potential participants (some children have more than two parents). Thirty-eight (16%) parents were excluded, most due to the time frame for the design or language difficulty. Of the remaining parents 156 (80%) have been included.

Conclusions: The study will hopefully generate new knowledge about whether certain factors act as risks or buffers for the development of PTSD among parents of children with cancer and brain tumours.

1280 POSTER

"I haven't done my homework today, my mother got cancer yesterday" An information video about children as relatives

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Background: Getting a cancer diagnosis implies a dramatic change in the life situation of both the patient and the family. When parents are sick, children's daily lives can be disrupted by worries and anxiety. Many parents are uncertain of how and how much they should tell the children about the illness. It's important that teachers in schools and kindergardens are competent to meet these children and their reactions.

Method: We have produced a 35 minute video with the subjects:

- When Mother and Father get cancer
- Being afraid
- Children want to help
- At the hospital
- School and kindergarden
- Return of illness
- To tell, or not to tell
- Looking for help

The participants in the video are families who themselves are struck by cancer. A psychologist gives advice on how adults can support and help children cope with daily living, and a teacher from a kindergarden tells from experiencing children as relatives.

Goal: That children in families where Mother or Father get cancer are better taken care of.

Results: 450 videoes are sold to schools, kindergardens, doctors, psychologist offices, school nurses, libraries etc. Several hundred families who are themselves struck by cancer, have, in addition, borrowed the video.

Responses from both families and professionals is that the video has been useful.