Proffered Papers

Rehabilitation

1120 ORAL

Rehabilitation - an integral part of treatment and nursing care for cervical cancer patients undergoing concomitant chemotherapy.

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Background: In 2001 the Copenhagen Hospital Corporation (H:S) and the Danish National Cancer Society granted funds for describing a project of which the scope is rehabilitation needs at the hospital for women with cervical cancer undergoing concomitant chemotherapy. Focus is to be on rehabilitation regarding the individual woman's body, family, and job situations. During 2002 a pilot cancer school (patient education) was developed as well as information retrieval for the project plan and interviews with formerly treated cervical cancer patients. The project was initiated at the Copenhagen University Hospital in March 2003 and will progress until the summer of 2005. The project is funded with 500.000 kroner (75.000 $ a year) by the H:S. The purpose is to improve the cancer patients' knowledge, support and self help ability to the extend that their lives after the treatment will be minimally influenced by the cancer and the side-effects from the treatment, and that the hospital staff will know to improve their focus and knowledge on rehabilitation for this matter.

Material and methods: The project consists of three parts: research, intervention, and evaluation. The research part will include using the new ICF classification (International Classification of Functioning and Disabilities) developed by WHO. During the project the managers of the involved units will describe treatments, procedures, organization, information etc. with the purpose of minimizing misunderstandings and improving collaboration between the units. The involved units are the radiation unit, out-patients' clinic, surgical ward, and oncology ward. The description of the course of patients events include describing the tasks and actions of the nurse, the doctor and the interdisciplinary team. The intervention part will include both patients as well as the nurse staff in contact with the patients. For the nurse staff there is a 3 day course optimizing their skills on the disease, treatment, nursing care, and rehabilitation. For patients there is a rehabilitation conversation at the end of their treatment period. 6 weeks after treatment the patient has to choose between either a second individual rehabilitation conversation or cancer school with other female gynaecological cancer patients. During the project period an weekly dedicated telephone consultancy with a nurse specialist is established. The evaluation part consists of questionaries on the subjects right after the treatment and after three and six month. Furthermore focus interviews will be held for both patients and nurse staff.

Conclusions: The project will include patients from September 2003 through July 2004 and ideally include around 50 patients. A total of 16 nurses from involved units will be educated as cervical cancer specialists.

1121 ORAL

Surviving cervical cancer: sexual health and psychosocial morbidity

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Background: Cancer and its treatment is well known to cause adverse effects which can influence patients' physical and psychosocial well being. In particular, for women, multi-modality treatment for gynaecological cancers can have a major impact on sexual health and quality of life. Research evidence demonstrates that more than 50% of patients treated for cervical cancer experience sexual morbidity. This view is supported by the Department of Health Guidelines, which emphasise the importance of research in this area. The evidence suggests the need for further investigation in order to develop the evidence base.

Materials and Methods: The aim of this study was to explore patients' sexual health following treatment for cervical cancer. A phenomenological research design was used to investigate the lived experience of women following treatment for cervical cancer. Qualitative interviews were conducted to explore experiences with an emphasis on psychosexual issues, particularly those relating to sexual health. A purposive sample of 13 patients was recruited from a primary group of 28. Eligibility criteria included women who were disease free but who received radical radiotherapy 2-3 years previously. Descriptive and interpretive codes were used to generate a series of themes from the data following Colaizzi's framework. Inter-rater reliability was obtained with a high degree of correlation between independent researchers.

Results: The study identified four major findings. First, the physical effects following treatment highlighted that 62% (n=8) of women experienced both bladder and bowel morbidity which in some cases affected their sexual health. Secondly, evidence of sexual morbidity, demonstrated that the late effects of treatment impacted on sexual health. Thirdly, a number of women demonstrated a high degree of adaptability to their changed lifestyle following radiotherapy. Finally, respondents expressed a need for more information regarding sexual health and the late effects of treatment.

Conclusions: The study raises a number of issues associated with the management of late treatment effects following cervical cancer. In particular, sexual morbidity and the need for more advice and information about the long-term implications of treatment. The study also has implications for the provision of effective health care and the psychosexual needs of cancer patients within a multidisciplinary framework.

1122 ORAL

SKUB-Nurses' consultation for women, who have received curative radiation therapy for breast cancer.

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We have taken the initiative to a development project based on our thesis, "The primary nurse as bridge builder ", at the in-service training of oncology in West Denmark 2001/2002.

The thesis was based on a visit to the radiation therapy ward at Malmø Hospital and on literature by Grethe Davidsen and Marlene Knøss.

In the thesis we concluded that patients felt a lack of quality in the transitional period between having finished their radiation therapy and their first doctors check-up, which is a period of 2-3 months. Some patients lack a sense of coherence in the process and this period is related to a feeling of insecurity and anxiety concerning their illness. It shows that some patients in this period are in need of discussing issues of physical, mental, social and spiritual character and for this they need counselling, active listening and support of self caring.

- **Physically:** insecurity concerning whether skin reactions, fatigue and site-effects to antihormonal treatment are normal
- **Mentally:** anxiety, fear, anger and difficulty in accepting a changed body image.
- **Socially:** a change of role from ill to well, and problems related to the job situation
- **Spiritually:** thoughts of faith, hope, life and death.

We want to evaluate the value of the nurses' consultation and decide whether it is the right way to prevent lack of quality and create support and sense of coherence, in the period of time from finishing radiation therapy and to the first doctors' check-up, for women who have received curative radiation therapy.

We plan to include 200 women in this evaluation. The patients are offered two visits at the nurses' consultation, 10 and 30 days after finishing the radiation therapy. Patients will meet the same nurse, who has been their primary nurse during the period of treatment. We plan to give the patients a questionnaire after each visit. Results of this project will, according to the time schedule, be ready for recommendation by December 2004

It is a demand from the Ministry of Public Health, that a general quality assurance of radiation therapy is being made. We see this development project as part of making a quality of assurance of the patients period of rehabilitation, being the period between finishing radiation therapy and first doctors check-up. According to The National Cancer Strategy, the hospital should be aware of patients' needs of rehabilitation, and actively participate in developing methods, contents and structure, that can fulfil patients' needs in this area. This project is to be seen as an effort of rehabilitation.

1123 ORAL

Women's perceptions of seroma and their drainage following mastectomy and axillary lymph node dissection

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Aim: The aim of this research was to study the effect of seroma on women's perception of daily functional and emotional status after surgical treatment for breast cancer. Furthermore, the experiences of the actual drainage procedure of seroma was studied.

Method The study had a prospective and comparative design. A study specific questionnaire was developed and used. Eighty-two women operated with modified radical mastectomy completed the forms. Forty-one women with seroma were compared with the 41 without seroma. The items focused on women's perceptions of daily life situations, postoperative pain, problems with the surgical scar, preoperative information, general health, levels of anxiety, depression, psychosocial support and contact with the registered nurse in the hospital.

Results Overall the perceived emotional and functional status, pain and general health did not differ between the two groups. Women with seroma contacted the registered nurse in the hospital more frequently after hospital discharge. Most women with seroma had no or little pain and anxiety during the aspiration and found the procedure fully acceptable. Practical information concerning self care and the aspiration procedure was considered insufficient. The return visit to the nurse for wound observation was important and provided psychosocial support.

Conclusion Seroma and its drainage is well accepted. Patients should be better informed about the possibility of a seroma and its treatment. Staff continuity and particularly the presence of a special trained nurse for wound control and for psychosocial support are much appreciated.

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1124 ORAL

Rehabilitation in cyberspace. Electronic support communities for breast cancer patients.

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Background: In the last years the Internet has brought new challenges to patient and health system. The aim of this study was to explore how the sharing of one's story of living with breast cancer, on an Internet mailinglist, creates communal counteraction to the isolation of illness experience.

Material and methods: The research is an ethnographic fieldwork conducted from April to December 2000 on the Scandinavian Breast Cancer Mailinglist (SCAN-BC-list) hosted by ACOR (Association of Cancer On-line Resources; www.acor.org).

The study was designed as a qualitative case-study. Data was produced through methods of participant observation, on-line interviews and focus-group interviews, as well as face-to-face interviews and the keeping of diaries.

Results: The study found that the mailinglist provides a space in Cyberspace where experience can be voiced and shared through storytelling. The Internet in this way works to mediate genuine social relations. Storytelling constitutes a way of sharing experience. In this way the Internet mailinglist holds great therapeutic value to its users, similar to conventional support groups. The mailinglist works to promote rehabilitation of the women, as the solitary experience of breast cancer is transformed into a social experience.

The observations made on the mailinglist reflect how writing and sharing a story in an Internet community leads to the articulation and transformation of the individual illness experience, as it offers the women a mode of action. By focussing on storytelling as action, narrative and action are drawn into an interpretive relationship in this study. The experience of illness is not just submissively suffered by the women on the mailinglist, but a passage from isolation to active participation in a new social context is facilitated through storytelling.

Conclusions: This study suggests that Internet support communities can form a crucial impact on the well-being and rehabilitation of cancer patients. Providing cancer patients and survivors with a way to share information and experience, the Internet communities form counteractions to the social isolation often following critical illness.

The Internet can be viewed as a strategy of empowerment to cancer patients, where the singular and isolated experience of illness is bridged to a shared and social experience of illness.

1125 ORAL

You have been very lucky, there is no need for after-treatment

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"You have been very lucky, there is no need for after-treatment".

A message like this is always a good message. Patient and family are relieved. They often wish to leave the hospital in a hurry, get on whit their daily life, and try to forget that they "have suffered from a small cancer".

However, the experienced nurse nurse will know from her clinical observations and from several studies, that cured cancer patients in general not seldom are having severe problems with fear of recurrence, lowered selfesteem, altered body-image and fatique.

It has furthermore been documented, that cancer patients, merely cured by operation, are often overlooked by the proffesionals. That their needs for support, education and counseling are beeing neglected. But rehabilitation is at the same time considered as very important, when there is good life expectancy and no disability. Women treated for early stages of cancer of the cervix uteri with radical hysterectomi are therefore in need of rehabilitationprograms designed to satisfy their special demands. The problem is, that we do still not know the precise caracter of these women's special needs.

An ongoing study in a gynaecological ward at Skejby Sygehus, Aarhus, Denmark, aims to produce results, wich makes designing such a programe on a evidence basis possible: A total of 400 women who have been operated for early stages of cancer of the cervix in the years 1983 ñ 2000 are asked about the impact of cancer on daily living and on general health, using among others the questionnaires SF-36 and Sence of Cohense (Antonowsky). Furthermore a number of 9 women are being folowed during a course in rehabilitation at The Danish Cancer Society and are interviewed 3 months and 1 year after their participation. Finally 7 qualitative interviews are being made with women, who claims that their rehabilitation has been sufficient.

Data are being analysed with ICF as a golden standard, and the theory of nursing and of a persons fundamental needs by Virginia Henderson as a conceptual and analytic frame. Results are to be published in spring 2004.