

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.

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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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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.

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### 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 with their daily life, and try to forget that they "have suffered from a small cancer".

However, the experienced 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 self-esteem, altered body-image and fatigue.

It has furthermore been documented, that cancer patients, merely cured by operation, are often overlooked by the professionals. That their needs for support, education and counseling are being 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 hysterectomy are therefore in need of rehabilitation programs designed to satisfy their special demands. The problem is, that we do still not know the precise character of these women's special needs.

An ongoing study in a gynaecological ward at Skejby Sygehus, Aarhus, Denmark, aims to produce results, which makes designing such a programme on an evidence basis possible: A total of 400 women who have been operated for early stages of cancer of the cervix in the years 1983-2000 are asked about the impact of cancer on daily living and on general health, using among others the questionnaires SF-36 and Sense of Cohesion (Antonovsky). Furthermore a number of 9 women are being followed 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 claim that their rehabilitation has been sufficient.

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