

When Breast Cancer Returns
Women's Experiences of Health, Illness and Adjustment
During the Breast Cancer Trajectory

Akademisk avhandling

som för avläggande av filosofie doktorsexamen
vid Sahlgrenska akademien vid Göteborgs universitet
kommer att offentliggöras i Hedlundsalen, Ängårdsbacken
fredagen den 11 april 2008 kl.10.00

av

Elisabeth Kenne Sarenmalm

Fakultetsopponent:
Professor Christina Bolund
Radiumhemmet, Stockholm

The thesis is based on the following papers:

- I Kenne Sarenmalm, E., Odén, A., Öhlén, J., Gaston-Johansson, F., Holmberg, S., & Bernhard, J., Changes in health-related quality of life predict recurrent breast cancer. (Submitted for publication).

- II Kenne Sarenmalm, E., Öhlén, J., Jonsson, T., & Gaston-Johansson, F., (2007). Coping with recurrent breast cancer - predictors of distressing symptoms and health-related quality of life. *Journal of Pain and Symptom Management* 34(1): 24-39.

- III Kenne Sarenmalm, E., Öhlén, J., Odén, A., & Gaston-Johansson, F., (2007). Experience and predictors of symptoms, distress and health-related quality of life over time in women with recurrent breast cancer. *Psycho-Oncology*. 2007 Sep 20; [Epub ahead of print].

- IV Kenne Sarenmalm, E., Thorén-Jönsson, A-L., Gaston-Johansson, F., & Öhlén, J., Making sense of living under the shadow of death – Adjusting to a recurrent breast cancer illness. (Submitted for publication).

When Breast Cancer Returns Women's Experiences of Health, Illness and Adjustment During the Breast Cancer Trajectory

Elisabeth Kenne Sarenmalm
Institute of Health and Care Sciences, the Sahlgrenska Academy
at UNIVERSITY of GOTHENBURG
Gothenburg, Sweden

Abstract

Although a recurrence of breast cancer is associated with significant distress, affecting health-related quality of life (HRQOL), little is known about women's experience during the recurrent breast cancer trajectory.

The primary aim of this thesis was to explore women's experiences of health, illness and adjustment to a recurrence of breast cancer. Both deductive and inductive methods were used. The first aim was to explore whether HRQOL factors predicted recurrence. The second aim was to explore distress, symptoms and HRQOL, over time in women with recurrent breast cancer. The third aim was to explore what major concerns these women experienced and how they deal with them, living with a recurrent breast cancer. The four papers included in this thesis are based on selected quantitative data (Papers I-III) and qualitative data (Paper IV).

Exploratory findings suggest that changes in physical wellbeing and nausea/vomiting may predict recurrence. Women with recurrent breast cancer experience multiple, concurrent, and persistent symptoms. Nearly ninety percent of the patients reported fatigue at the time of recurrence. Women with a strong sense of coherence reported a lower prevalence of symptoms and experienced lower levels of distress and better perceived adjustment to their illness, as well as perceived a better health and quality of life. Distress had a major impact on HRQOL. Over time, women adjusted to the many implications of a life-threatening illness through personal transition. By making sense of living with a threat to their lives, the women adjusted to their recurrence.

The findings highlight the major existential impact of a recurrence. Promoting health is possible, even in severe illness and in unchangeable and almost unbearable situations. Opportunities to manage adversity remain. Women may transcend their illness by finding new meaning through discovering or re-discovering significant values in life, and creating wellness by being in the present moment.

Key words: Recurrent breast cancer, health, illness, adjustment, health-related quality of life, sense of coherence, distress, symptoms