



GÖTEBORGS UNIVERSITET
SAHLGRENSKA AKADEMIN

PSYCHOSOCIAL SUPPORT NEEDS AFTER A BREAST CANCER DIAGNOSIS

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Sahlgrenska
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av

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Avhandlingen baseras på följande delarbeten:

- I. **Stinesen-Kollberg K.M., Thorsteinsdottir T., Wilderäng U., and Steineck G.**
"Worry about one's own children, psychological well-being, and interest in psychosocial intervention".
Psycho-Oncology 2013; **22**(9): 2117-23.
- II. **Stinesen-Kollberg K.M., Wilderäng U., Möller A., and Steineck G.**
"Worrying about one's children after breast cancer diagnosis: desired timing of psychosocial intervention".
Submitted
- III. **Stinesen-Kollberg K.M., Wilderäng U., Möller A., and Steineck G.**
"Struggling for a sense of control in order to be prepared: consequences of chemotherapy-related fear among women diagnosed with breast cancer".
Submitted
- IV. **Stinesen-Kollberg K.M., Möller A., Steineck G., and Wilderäng U.**
"The straw that broke the camel's back: exploring the attributes of women with psychosocial support needs after a breast cancer diagnosis".
Submitted.

ABSTRACT

With a growing number of women surviving breast cancer each year in combination with limited health care resources, clinics are increasingly pushed to optimize psychosocial care as life after a breast cancer diagnosis not only is a question of survival, but also a question of how well one survives. In light of this pressure, it becomes important to gain an understanding of women's own psychosocial care needs. We were interested in all aspects of psychosocial care, however, our primary hypothesis was that the major area of concern would be issues centering one's sexual health. Also, we wanted to investigate the psychosocial support needs for twelve psychosocial problems commonly brought up in clinic. Through a population-based registry, we identified 511 women who had undergone surgery for breast cancer at the Sahlgrenska University Hospital, Gothenburg, Sweden. During a 14-month qualitative phase, we constructed a study-specific questionnaire comprising 126 questions based upon the themes that emerged from in-depth interviews.

We analyzed data from 313 eligible respondents. In **paper I** we found that worrying about one's own children was significantly associated with low psychological well-being during the year that followed breast cancer surgery (relative risk 2.63; 95% CI 1.77-3.90; posterior probability value 98.9%). In **paper II** we found that of those who did not receive chemotherapy treatment, 70 out of 112 women (63%), reported a desire to receive support about the worry about their children and of those who received chemotherapy treatment, 20 out of 49 (41%), reported a need for support immediately following diagnosis before surgery. We identified having children at home ($P<0.0001$), worry about sex life ($P=0.0009$), fear of dying from breast cancer ($P=0.0055$), and worried about one's personal financial situation ($P=0.0413$) as the variables most closely related to worry about the children. Results in **paper III** showed that there was no statistically significant difference between the group receiving chemotherapy when compared with the group not receiving it (fear of hair loss: age adjusted $P=0.5120$ and fear of nausea: age adjusted $P=0.7230$). Both groups reported a desire to receive psychosocial support immediately following diagnosis. In **paper IV**, we found that those who desired psychosocial intervention, but for some reason never received it, possessed either one or more of the following four attributes: 59 years of age or younger, children living at home, treated with chemotherapy, and low psychological well-being at some point during the year that followed diagnosis. ($P<0.0001$). Also, the very same demographic- and treatment-related attributes were identified among those who did receive psychosocial treatment.

Conclusions: Data show that there is an association between worrying about one's children and low psychological well-being. Additionally, women wish to talk about their worry about their children early in the treatment process. They also have a desire to receive basic information about treatment-related issues as early as possible, specifically including side-effects from chemotherapy treatment. When exploring the profiles of the women were 1) interested in, and 2) received psychosocial intervention, we found that mothers with children at home, who had undergone chemotherapy treatment, and whose mental health was affected during the year after diagnosis, were at an elevated risk. We believe that if we want to better the situation for breast cancer survivors in a health care system where resources are scarce, we should immediately after diagnosis offer the mother structured psychosocial support with specific focus on her children and also offer her basic information concerning chemotherapy treatment.

Keywords: Breast cancer, quality of life, psychosocial needs, parenting, children, psychological well-being, timing, chemotherapy, perception.

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