

# Designing, developing and evaluating a person-centered support model for women with breast cancer treated with endocrine therapy

## Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligens försvaras i Arvid Carlsson, Academicum, Medicinaregatan 3 fredag den 20 maj, klockan 13.00.

av

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### Avhandlingen baseras på följande delarbeten

- I. Ahlstedt Karlsson, S, Wallengren, C, Olofsson Bagge, R, Henoch, I. (2019). "It is not any pill" – women's experiences with endocrine treatment after breast cancer surgery. *European Journal of Cancer Care*. DOI:10.1111/edc.13009
- II. Ahlstedt Karlsson S, Wallengren C, Olofsson Bagge R, Henoch I. (2019). Women's coping strategies during the first three months of adjuvant endocrine therapy for breast cancer. *Nurs Open*.7(2):605-612. DOI:10.1002./nop2.430
- III. Ahlstedt Karlsson S, Henoch I, Olofsson Bagge R, Wallengren C. (2021). An intervention mapping-based support program that empower patients with endocrine therapy management. *Evaluation and Program Planning*. 92(11):10207. DOI: 10.1016/j.evalprogplan.2022.102071
- IV. Ahlstedt Karlsson S, Henoch I, Olofsson Bagge R, Wallengren C. (submitted). A person-centered support program (RESPECT intervention) for women treated with endocrine therapy: A feasibility study

# Designing, developing and evaluating a person-centered support model for women with breast cancer treated with endocrine therapy

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## Abstract

Breast cancer is the most common cancer among women worldwide. Approximately 70% of all breast cancers are estrogen positive and are recommended for treatment with adjuvant endocrine therapy (ET) for five to ten years, which significantly reduces mortality rates. However, problems related to ET can be experienced by patients. The **overall aim** of this thesis is to design, develop and evaluate a person-centered support model (PSM) to empower patients with breast cancer treated with ET. This PSM will be delivered by a nurse navigator at a surgical outpatient clinic.

The **methods** used included focus group interviews (Study I) with 25 patients approximately three years after they started ET. A mixed method study (Study II) was performed that included 39 patients who described their first three months of experience with their ET in a diary. Intervention mapping was used in Study III to design and develop a PSM using an action research design. Study IV tested the feasibility of the PSM with 20 patients in a control group and 21 patients in an intervention group using a quasi-experimental design. Three questionnaires regarding patient self-efficacy, perceived symptoms and quality of care were administered at baseline and after three months.

The **findings** showed that ET needed to be managed due to side effects but also that prior knowledge caused hesitation. The analysis resulted in three categories that described patients' experiences: ET *created discomfort*, patients experienced *feelings of abandonment*, and the most frequently reported *problem was sleeping difficulties*. Patients used both emotion- and problem-focused coping mechanisms. In the development of the PSM, patients' diverse views of ET and needs were highlighted, and a support model built upon a person-centered approach seemed appropriate. The PSM was evaluated for its feasibility. Ninety-five percent of patients completed the PSM. The preferred follow-up was by telephone, and up to four follow-up sessions were held during the 12-week intervention. There were no significant differences in patient self-efficacy, perceived symptoms, or quality of care between the control and intervention groups.

The **conclusion** is that the PSM was perceived to be feasible in terms of its process, resources, scientific challenges and acceptability among patients.

**Keywords:** Breast cancer, Coping, Empowerment, Endocrine therapy, Intervention mapping, Patients' experience, Person-centered care, Support model