

"The Involuntary Journey Beyond Treatment – Uncovering the Hidden Struggles of Women with Hormone-Sensitive Early Breast Cancer in Sweden"

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INTRODUCTION

Breast cancer is the most prevalent form of cancer among women worldwide. Survival rates have improved considerably, particularly for early-stage, hormone-sensitive breast cancer. Nevertheless, patients continue to encounter emotional, psychological, and informational challenges throughout their cancer journey. It is imperative to comprehend these challenges to improve support systems and healthcare interventions. The aim of this study is to identify gaps within healthcare systems that impact the lived patient experience, particularly in the pre-diagnosis, peri-diagnostic, post-diagnosis, and survivorship phases.

METHODS

A qualitative study utilizing semi-structured interviews with 49 women diagnosed with hormone-sensitive, non-advanced breast cancer within the last five years. Participants were recruited through Swedish patient organizations and selected based on age, socioeconomic and demographic diversity. Interviews were conducted digitally, transcribed verbatim, and analyzed using content analysis. The study received approval from the Swedish Ethical Review Authority in January 2024 (approval number 2023-07880-01).

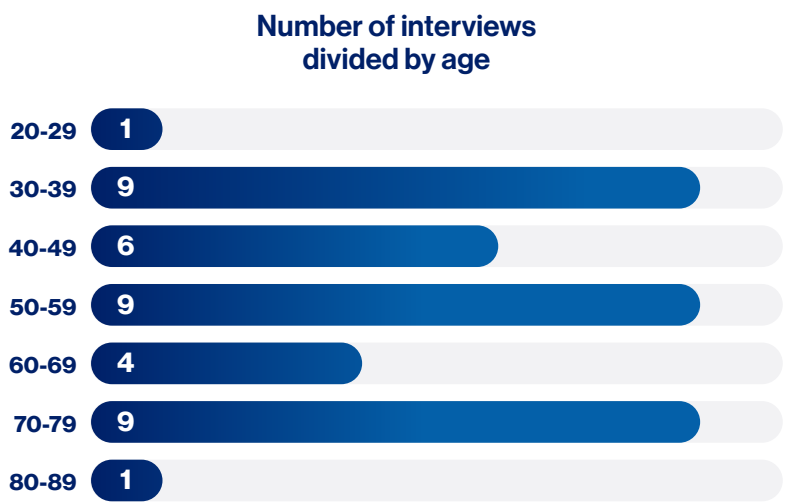


Figure 1. The age distribution of participants

RESULTS

Sweden is an elongated country offering a diverse array of environments, with uneven distribution of medical resources around the country and varied health care access. Hence for selection we used purposive sampling to ensure a diverse representation not only in terms of age (*Figure 1*), cancer stage (II or III), socioeconomic status, ethnicity, but also geographic location within Sweden (*Figure 2*).

Four key transitions were identified in the women's cancer trajectories: from healthy to sick, individual to patient, visible to invisible, and secure to vulnerable. These transitions encompassed emotional, psychological, and physical challenges throughout the care continuum. Many women reported a lack of follow-up care and insufficient support during antihormonal therapy, leading to feelings of abandonment and invisibility. Side effects such as joint pain, fatigue, and emotional distress were pervasive and influenced daily functioning and treatment adherence.

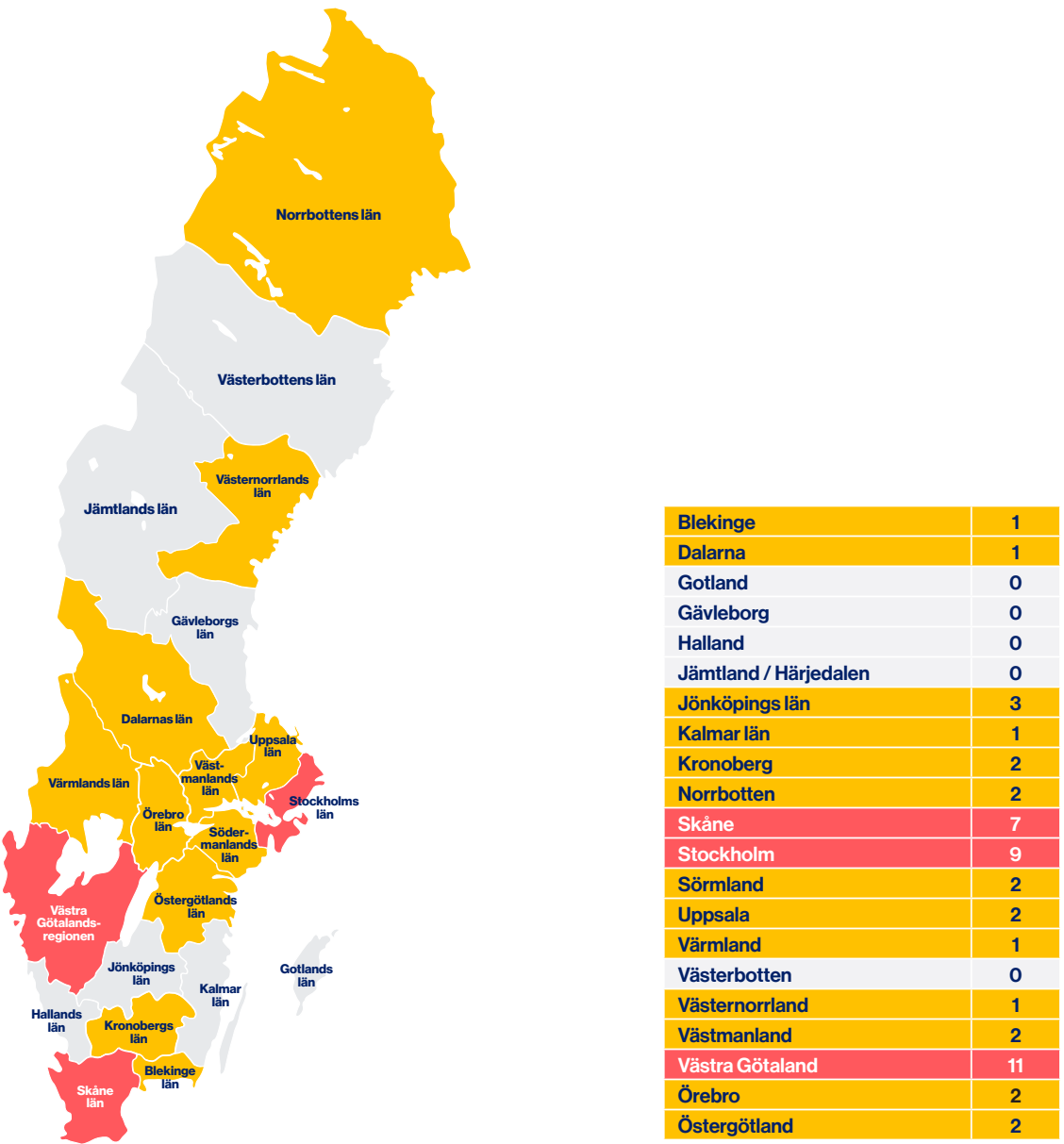


Figure 2. The geographic distribution of participants

CONCLUSIONS

This study provides novel and comprehensive insights into the transitional experiences of women undergoing long-term antihormonal therapy for early-stage hormone-sensitive breast cancer. This study underscores the urgent need for long-term, person-centred support, beyond the initial treatment phase. The identified transition phases (*Figure 3*) reflect the profound life changes patients experience, from being healthy to sick and from feeling safe to unsafe. To improve patient experiences, it is crucial to prepare patients for the long and often difficult treatment process. This includes providing the necessary information and emotional support, as well as equipping patients with tools for self-care. Empowering patients with strategies to manage the challenges they face can help them navigate their path to recovery.

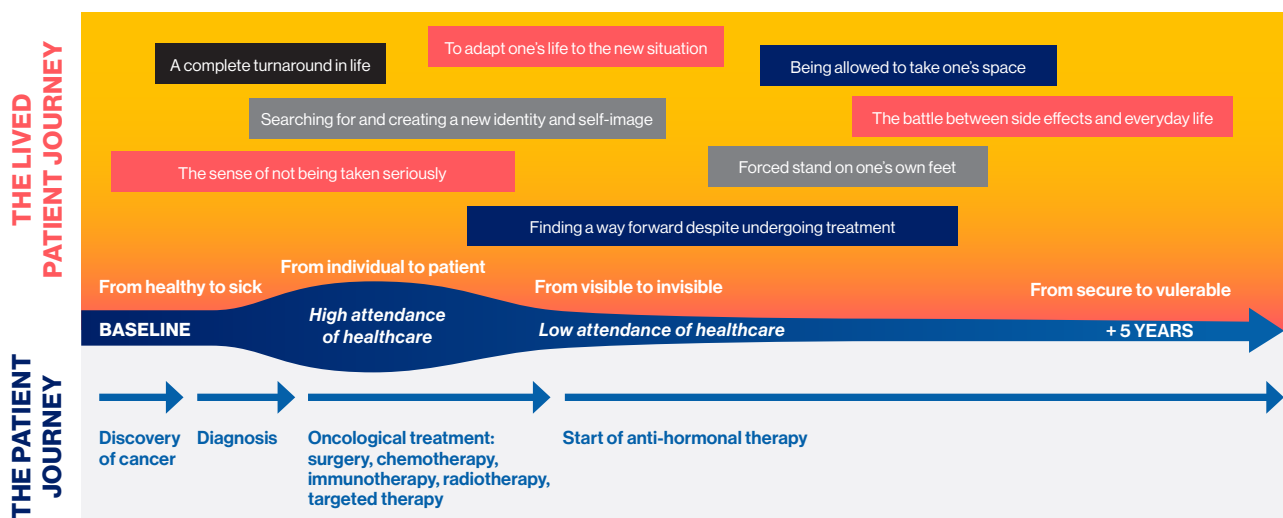


Figure 3. The Lived Patient Journey

DISCLOSURE OF FUNDING SOURCE AND CONFLICTS OF INTERESTS

Novartis Sweden was the initiator for the study, Gothenburg University was the principal investigator. The two main national patient organizations for cancer and breast cancer, and University of Gothenburg – Center for Person-centered care was contacted by Novartis in 2023 for discussions regarding a study proposal. Although the study was partially funded by a pharmaceutical company in the preparatory phase, The Presenter has no other conflicts of interest to disclose.

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