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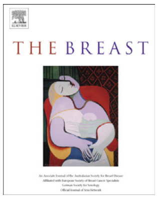

Original article

Disentangling breast cancer patients' perceptions and experiences with regard to endocrine therapy: Nature and relevance for non-adherence

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ABSTRACT

Background & study aims: Adjuvant endocrine therapy effectively prevents recurrence and progression of estrogen-receptor positive breast cancer. However, studies reveal substantial non-adherence. The objective was therefore to identify the nature of the experiences and beliefs of women treated with endocrine therapy in an attempt to find potential determinants of non-adherence.
Method: Online Focus Groups (OFGs) and individual interviews were conducted with 37 women who were treated with endocrine therapy. Sixty-three statements derived from the OFGs and 11 belief items from the Beliefs about Medicines Questionnaire (BMQ) were used in a Q-sorting task conducted with 14 of the women. The quantitative Q-sorting data were statistically analyzed with Hierarchical Cluster Analysis.
Results: A six cluster solution was revealed that included the clusters 'information', 'efficacy', 'tenacity', 'coping', 'side effects' and 'usage'. Women's own experiences and perceptions were not clearly delineated from the beliefs measured with the BMQ. However, women judged their own experiences and perceptions with regard to endocrine therapy as more relevant for adherence than the BMQ beliefs.
Conclusion: In order to understand and to improve women's adherence to endocrine therapy, women's own perceptions and experiences about endocrine therapy should be targeted in addition to common beliefs that apply to a wide range of medicines.

Introduction

Adjuvant endocrine therapy has improved the prospects of women with breast cancer markedly. Evidence shows that prolonged use of tamoxifen or an aromatase inhibitor strongly reduces the risk of estrogen-receptor-positive breast cancer recurrence, disease progression and mortality.[1–3] A contradictive finding is therefore that adherence to endocrine therapy seems to be almost as important a problem as it is for such medicines as statins.[4] Studies have found substantial non-adherence by the fourth year of therapy[5] and premature discontinuation by 30%–50% of the patients.[6,34] Non-adherence to endocrine therapy is a serious problem that is associated with increased mortality.[7]

Understanding non-adherence to endocrine therapy is therefore crucial for clinicians. Clinicians who are aware of the obstacles that women encounter are better at promoting adherence to endocrine therapy and in the end women's health.[9] However, understanding the causes of non-adherence to endocrine therapy is compromised by a number of factors. First, the causal structure of endocrine therapy non-adherence is likely to be multifaceted. Over 200 predictors of adherence to a wide range of medicines have been postulated.[8,9] Which of these factors are especially relevant for endocrine therapy non-adherence remains unclear. Second, a comprehensive overview of factors lacks, as different studies have addressed different factors. Third, many studies focused on beliefs about medicines. For that goal, the Beliefs about Medicines

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Questionnaire (BMQ) framework has often been used to assess perceived necessities and concerns with regard to medicine use and the calculation of a difference score thereof called the necessity-concerns differential.[10,11] The BMQ has been used to explain adherence to various types of medicines.[12–18] With regard to endocrine therapy, non-adherent patients were found to report beliefs of inefficacy of tamoxifen more often.[19] However, as important as beliefs that apply to a wide range of medicines are women's own perceptions and experiences with regard to endocrine therapy. Atkins and Fallowfield,[22] for example, found that women who disliked any aspect of their current endocrine therapy (e.g. side effects and difficulties swallowing tablets) were more likely to be non-adherent. Accordingly, the aim of this study was to provide a comprehensive overview of women's beliefs and experiences with regard to endocrine therapy. We examined (a) which clusters of beliefs and experiences could be identified, (b) whether experiences and beliefs regarding endocrine therapy formed separate clusters and (c) how relevant each cluster of beliefs and experiences was for therapy adherence.

Patients and methods

Participants

We identified all breast cancer patients who had been or were being treated with endocrine therapy at the outpatient oncology clinic of the Leiden University Medical Center (LUMC), the Netherlands ($n = 175$). A total of 54 patients had to be excluded for the following reasons: metastatic disease, severe or terminal illness or unclear health status, psychiatric disorders, regimen completion >1 year ago to avoid recall bias, and language problems. Therefore, 121 patients were invited to participate of whom 30 patients responded positively. Another 7 women responded to our call posted on the website of a patient organization (see Fig. 1 Flowchart of participant recruitment). All 37 participating women returned a complete informed consent form along with a questionnaire by means of which we assessed demographic and clinical characteristics and therapy adherence using the Medication Adherence Rating Scale (MARS) (R. Horne, M. Hankins, unpublished). The medical ethical committee approved the study (protocol number CME10/145). Table 1 shows that there was ample variation in demographic and clinical characteristics of the participants.

Research design

The study consisted of two phases. In Phase I, Online Focus Groups (OFGs) were conducted to identify women's beliefs and experiences with regard to endocrine therapy. In Phase II, following the methodology by Kool et al.,[23] the discussions of these OFGs were quantified by means of a Q-sorting task enabling a statistical analysis of the sorting data.[23]

Phase I: Online Focus Groups

OFGs[24] were conducted by two members of the research team (LvD and HW) to identify women's beliefs and experiences with regard to endocrine therapy ($n = 31$). Women were individually interviewed if they did not have internet access ($n = 3$) or when they had prematurely discontinued endocrine therapy ($n = 3$). Premature discontinuation was defined as discontinuation before

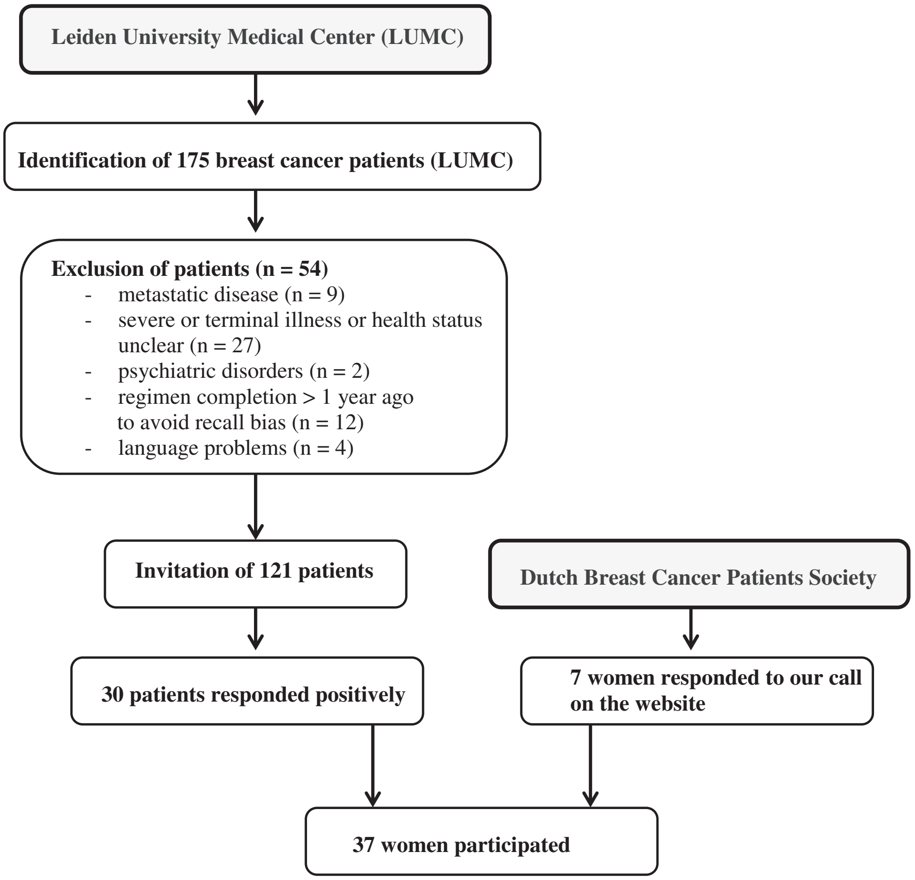

Fig. 1. Flowchart of participant recruitment.