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Patients' experiences with decisions on timing of chemotherapy for breast cancer

K.M. de Ligt [a, b, *, 1], P.E.R. Spronk [c, f, 1], A.C.M. van Bommel [c, f], M.T.F.D. Vrancken Peeters [d], S. Siesling [a, b], C.H. Smorenburg [e], on behalf of the Nabon Breast Cancer Audit group

[a] Department of Research, Netherlands Comprehensive Cancer Organisation (IKNL), Godebaldkwartier 419, 3511 DT, Utrecht, The Netherlands
[b] Department of Health Technology and Services Research, MIRA Institute for Biomedical Science and Technical Medicine, University of Twente, Drienerlolaan 5, 7522 NB, Enschede, The Netherlands
[c] Department of Surgery, Leiden University Medical Centre, Albinusdreef 2, 2333 ZA, Leiden, The Netherlands
[d] Department of Surgery, Netherlands Cancer Institute - Antoni van Leeuwenhoek, Plesmanlaan 121, 1066 CX, Amsterdam, The Netherlands
[e] Department of Medical Oncology, Netherlands Cancer Institute - Antoni van Leeuwenhoek, Plesmanlaan 121, 1066 CX, Amsterdam, The Netherlands
[f] Dutch Institute for Clinical Auditing (DICA), Rijnsburgerweg 10, 2333 AA, Leiden, The Netherlands

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ABSTRACT

Introduction: Despite potential advantages, application of chemotherapy in the neo-adjuvant (NAC) instead of adjuvant (AC) setting for breast cancer (BC) patients varies among hospitals. The aim of this study was to gain insight in patients' experiences with decisions on the timing of chemotherapy for stage II and III BC.

Materials and methods: A 35-item online questionnaire was distributed among female patients (age>18) treated with either NAC or AC for clinical stage II/III invasive BC in 2013–2014 in the Netherlands. Outcome measures were the experienced exchange of information on the possible choice between both options and patients' involvement in the final decision on chemotherapy timing. Chemotherapy treatment experience was measured with the Cancer Therapy Satisfaction Questionnaire (CTSQ).

Results: Of 805 invited patients, 49% responded (179 NAC, 215 AC). NAC-treated patients were younger and more often treated in teaching/academic hospitals and high-volume hospitals. Information on the possibility of NAC was given to a minority of AC-treated patients (AC, stage II:14%, stage III: 31%). Information on pros and cons of both NAC and AC was rated sufficient in about three fourth of respondents. Respondents not always felt having a choice in the timing of chemotherapy (stage II: 54% NAC vs 36% AC; stage III: 26% NAC, 54% AC).

Conclusion: The need to make a treatment decision on NAC was found to be made explicit in only a small number of adjuvant treated patients, in particular in BC stage II. Less than half of the respondents felt they had a real choice.

1. Introduction

Breast cancer (BC) care consists of a multidisciplinary approach of surgery, radiation, and systemic therapy including chemotherapy [1]. Chemotherapy intents to eliminate potential existing micrometastases, thus decreasing recurrence rates and mortality [2]; it is timed either prior to or following surgery, respectively neo-adjuvant (NAC) or adjuvant (AC), both leading to similar disease free and overall survival [1,3,4]. NAC versus AC yields several advantages. Down-staging of the primary tumour increases resectability and the possibility of breast conserving surgery (BCS) [4] and axillary preserving surgery [5]. Moreover, the response to chemotherapy can be assessed [1,3,4,6], creating a platform to study the activity of (novel) agents or therapeutic combinations in a patient-personalized way [3,4,7,8].

(Inter)national BC guidelines recommend NAC over AC for patients with locally advanced BC (stage III) aged <70 years, while

* Corresponding author. Netherlands Comprehensive Cancer Organisation (IKNL), Department of Research, Godebaldkwartier 419, 3511 DT, Utrecht, the Netherlands.
E-mail addresses: k.deligt@iknl.nl (K.M. de Ligt), p.spronk@dica.nl (P.E.R. Spronk), a.c.m.van_bommel@lumc.nl (A.C.M. van Bommel), m.vrancken@nki.nl (M.T.F.D. Vrancken Peeters), s.siesling@iknl.nl (S. Siesling), c.smorenburg@nki.nl (C.H. Smorenburg).
[1] Contributed equally.

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NAC can also be considered for patients with stage II BC with a clear indication for adjuvant chemotherapy [1,9,10]. The use of NAC for early BC is increasing, but despite its advantages, NAC is still applied less frequently than AC [11]. In the Netherlands, 12% of all newly diagnosed BC patients was treated with NAC in 2014, whereas in that same year 31% of patients received AC. Also, a considerable variation (0–97%) in NAC-application between hospitals was observed [12]. Significant predictors for the use of NAC (stage III) appeared to be young age, a diagnostic MRI, large tumour size, advanced nodal disease and a negative hormone receptor status. However, not all variation could be explained by tumour and patient characteristics [13], implicating that other factors play a part in the timing of chemotherapy. Nowadays, treatment decisions are shared between the physician and patient. Important in the process of shared decision-making (SDM) is that both patient and physician are aware of a decision being required, knowing and understanding all available information on treatment options, and sharing the decision by incorporating both the physicians advice as the patient's preferences [14]. Therefore, the goal of this study was to gain insight in patients' experiences with decisions on the timing of chemotherapy for stage II and III BC.

2. Materials and methods

2.1. Study population

Fifty-two hospitals were invited to participate; nineteen were willing to cooperate. We attempted an equal distribution in hospital volume (low, middle, high) and type (general, teaching, academic), and an equal geographical scatter. Patients of these hospitals were selected from the Netherlands Cancer Registry (NCR): a nationwide registry in which all newly diagnosed cancer patients are registered, hosted by the Netherlands Comprehensive Cancer Organisation (IKNL), which includes all items for the NABON Breast Cancer Audit [12]. We selected surgically treated patients (aged 18 or older) who were diagnosed with primary invasive BC stage II/III between 2013 and 2014 and received NAC or AC. Patients with previous malignancies and/or metastases were excluded. A sub-set of 40–50 patients per participating hospital was randomly selected, with an average of 43 per hospital.

A total of 805 patients (367 NAC-treated, 438 AC-treated) were invited by a letter through their treating physician between August 24th, 2015 and January 1st, 2016 to participate in our online questionnaire. The survey was offered within a secured web-based environment named PROFILES [15]; paper questionnaires were provided on request. Completed questionnaires were collected until the 28st of February 2016. Respondents gave consent on an adjective (online) form for processing their answers and merging them to their clinical data available in the NCR. Approval from the Committee of Privacy of the NCR and the Medical Ethical Committee of the Netherlands Cancer Institute - Antoni van Leeuwenhoek were obtained for this study.

2.2. Questionnaire

The thirty-five-item questionnaire (appendix A) consisted of questions on SDM, completed with questions on the patients' experience and satisfaction with chemotherapy care in general. SDM was defined as by the study of Légaré et al.: both health care provider and patient recognise and acknowledge that a decision is required, while knowing and understanding all best available relevant evidence, taking into account both the patient's preferences and the provider's advice [14].

Questions (Q) 1 to 9 asked about general mental and physical health and timing and type of chemotherapy received. The following questions dealt with the conditions of SDM. To determine whether patients were *informed on the possible choice* between NAC and AC, patients were asked whether they received information on chemotherapy prior to surgery (Q10) and whether (Q11) and with whom (oncologist, surgeon, nurse practitioner, nurse specialised on BC, general practitioner; Q12) NAC was discussed. To assess whether *information on evidence of both options was provided*, patients were asked if pros and cons of both NAC and AC were discussed (Q13). To determine if *patient preferences* were taken into account, questions were posed on whether the patient understood on what arguments the final decision was made (Q14 to Q17, Q19). The patients experienced SDM was based on questions whether they felt they shared the decision on the timing of chemotherapy (Q18) and had enough time to make a decision (Q20). In addition, to determine the overall level of patient information we asked questions on chemotherapy treatment information in general (Q21 to Q24). To determine chemotherapy treatment experience, all questions from the Cancer Therapy Satisfaction Questionnaire (CTSQ) were included (Q25 to Q30), consisting of three domains: Expectation of Therapy (EOT), Feelings about Side Effects (FSE), and Satisfaction With Therapy (SWT) [16]. General items such as nationality, level of education, and living and working status were requested as well (Q31 to Q35). A patient panel contacted through the Dutch BC patient association (Borstkankervereniging Nederland) critically reviewed and adjusted the questionnaire in comprehensible language and added additional explanations.

2.3. Analysis

Completed questionnaires were merged with the clinical data registered in the NCR.

Generalisability of the results was determined by comparing characteristics of respondents to non-respondents (Pearson's chi-square). Furthermore, NAC-treated and AC-treated respondents were compared on patient, tumour, and treatment characteristics (Pearson's chi-square).

The answers to the questionnaire were assessed separately for stage II and III; NAC-treated compared to AC-treated patients. Conditions of SDM were chi-square tested, as well as the experience with general information on chemotherapy (Q21 to Q24). At last, treatment experience was described by calculating CTSQ-scores [17]: a score between 0 and 100 was assessed separately for each domain for respondents that answered a minimum amount of questions. Higher scores are associated with better responses (better therapy expectations, feeling less impact of side effects, and greater satisfaction with therapy). Means were calculated by the sum of all assessed scores divided by the number of respondents that a score was assessed to. Mean scores were compared using a T-test; we reported 95%-confidence intervals as well. Statistical significance was defined as a p-value <0.05 (two-sided).

All analyses were performed in STATA 14

3. Results

3.1. Respondents to questionnaire (Table 1)

A response rate of 49% (394/805) was reached; 179 (45%) NAC-treated patients versus 215 (55%) AC-treated patients. Respondents did not differ significantly from the non-respondents on patient (age), tumour (year of diagnosis, clinical stage, morphology), and hospital characteristics (volume, type). The ratio of NAC versus AC was comparable between respondents and non-respondents.

NAC-treated respondents were more often treated in a teaching