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Evaluation of the adherence to follow-up care guidelines for women with breast cancer

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A B S T R A C T

Purpose: To evaluate adherence with follow-up criteria as suggested by the national guideline for breast cancer patients.
Method: Patients diagnosed with breast cancer in 2003 in two hospitals were identified from the Netherlands Cancer Registry ($n = 198$). Compliance with the guideline was assessed retrospectively by extracting follow-up care data from patient files for a period of five years.
Results: Follow-up data were available for 196 patients. In the first year of follow-up, fewer consultations were performed compared to guideline standards. In the second through the fifth year of follow-up, more consultations were performed, with nearly double the number of consultations in the third until the fifth year compared to the guideline ($p < 0.05$). This excess usage was mainly associated with the fact that women had received radiotherapy ($p < 0.01$). Physical examinations were performed during 97 percent of consultations. Mammograms were performed slightly less often than suggested.
Conclusions: Among women receiving follow-up care after breast cancer, more consultations were provided compared to the guideline recommendations. Mammograms were performed slightly less often than recommended. With regard to the performance of physical examinations, the guideline was followed.

Introduction

Breast cancer is the most frequently occurring cancer among women in the Netherlands (van den Berg et al., 2002). In 1989, 7704 women were diagnosed with invasive breast cancer, a number which increased to 13,005 new cases in 2008 (NKR, 2010a). Due to improved treatment and early diagnosis, the five year relative survival has increased from 76% for women diagnosed in 1988–1992 to 85% for women diagnosed in 2003 (NKR, 2010b; Barrett, 2010). The first choice of treatment for invasive breast cancer is surgery, either breast conserving or mastectomy. Adjuvant treatment for breast cancer can include radiotherapy, chemotherapy, immunotherapy and/or hormone therapy depending on patient and tumour characteristics (NABON, 2002). Consequently, four disciplines are often involved in the care process of breast cancer patients: the general practitioner, surgeon, medical oncologist and the radiation oncologist (Janssen-Heijnen et al., 2005).

Women who received curative treatment for breast cancer are entitled to follow-up care. The period of follow-up starts after treatment of the primary tumour, which can include chemo- and radiotherapy. The follow-up has several aims, the main one of which is detection of recurrent curative treatable tumours, either local or regional, or a second primary tumour (ipsi-/contralateral) (NABON, 2008). In the Netherlands, 3% of all the patients that received breast conserving therapy developed a recurrence within five years (van der Heiden et al., 2010). Literature indicates that the majority of the recurrences can be observed within the first five years of follow-up. A peak in time of diagnosis of these recurrences can be observed at 24 months and possibly also at 60 months (Demichelli et al., 2008). There is no screening for asymptomatic distant metastases, since early detection and subsequent treatment does not improve survival (Demichelli et al., 2008; Allen, 2002). Except for the yearly mammogram, advanced diagnostic imaging is

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therefore not recommended in asymptomatic women (Allen, 2002). Other aims of follow-up include early detection and the treatment or monitoring of treatment side-effects, psychosocial counselling and recognizing serious mental problems (NABON, 1999).

There are different strategies for follow-up: follow-up comprising clinical visits and a yearly mammogram or a more intense follow-up including laboratory and radiology testing (Rojas et al., 2009). In a review, Rojas et al. (2009) suggest that, with regard to the detection of malignancies, the less intense follow-up (regular physical examinations and an annual mammography) is as effective as the more intense follow-up (regular execution of laboratory and instrumental examinations) (Rojas et al., 2009). In the Netherlands, a national guideline has been developed by the NABON (Nationaal Borstkanker Overleg Nederland) for the follow-up procedures after the treatment of breast cancer (NABON, 2002). This guideline states that women should receive follow-up care for a minimum of five years. The frequency of visits changes over the years: in the first year the woman should be seen four times, in the second year twice, and thereafter once a year. During these visits women receive a physical examination and once a year a mammogram. In 2008 the guidelines have been revised.

Due to the increase in incidence of breast cancer and the higher rate of survival, the burden on caregivers for breast cancer treatment and follow-up is growing. This can result in problems with regard to the number of follow-up consultations the breast cancer centre can conduct (Molino, 2010). Little information is available about the follow-up care provided and adherence to the national guideline in the daily life setting. The aim of this paper is to evaluate adherence with follow-up criteria as suggested by the national guideline and to determine the factors that influence the adherence to this guideline.

Methods

Study population

Patients were identified from the database of the Netherlands Cancer Registry. Based on pathological notification through the PALGA (automated pathology archive) system, trained registration clerks gather data concerning patient, tumour and treatment characteristics from the patients files. The topography and morphology are coded according to the International Classification of Diseases for oncology (ICD-O). Staging is coded according to the tumour, node, and metastasis system (TNM) classification (Wittekind et al., 2005).

Inclusion criteria were: women diagnosed in 2003 with invasive breast cancer, and curatively treated by means of surgery (breast conserving or mastectomy) in the Deventer Hospital (DH) (Deventer, the Netherlands) and the Medical Spectrum Twente (MST) (Enschede, the Netherlands). Exclusion criteria were: metastases at diagnosis and a simultaneous tumour in the other breast. In total 198 patients were selected.

Data collection

Additional patient-, tumour- and specific follow-up information were acquired from the patient files and the electronic patient records in the two teaching hospitals. In the MST, data regarding radiotherapeutic treatment and follow-up was obtained from the radiotherapeutic department within the hospital and, for the DH, from the radiotherapeutic centre "Radiotherapeutisch Instituut Stedendriehoek en Omstreken" (RISO, Deventer, the Netherlands). Data were collected from 2003 for a period of five years. This time frame was chosen to determine the consistency with the 5-year follow-up guideline. Ethical approval was obtained through the Committee of Privacy of the Cancer Registry.

During the study period, the 2002 NABON guideline was available for the follow-up of breast cancer patients. Adherence to this guideline was determined by the frequency of follow-up consultations and the performance of the annual mammogram. This study includes the follow-up consults with the surgeon and the radiation oncologist (including the consultations performed by interns, nurse practitioners, physician assistants and breast care nurses), because these health professionals were actively involved in the follow-up care in both hospitals. The "start of the follow-up period" was defined as the date of the end of the treatment, which was the date of surgery or the end date of adjuvant treatment (radiotherapy and/or chemotherapy) plus ten weeks. The ten weeks were added because it was difficult to distinguish routine post-treatment visits (e.g. wound control) and follow-up care in the first period after treatment. A distinction was made between women who received fewer consultations and/or mammograms (including routine MRI's for the mamma) compared to the guideline and women who received more consultations compared (excess use) to the guideline. During every consultation the woman should receive a physical examination. The following were recorded: the performer of the consultation, patient complaints, additional diagnostics and the outcome of the consultation.

To determine the rate of recurrent malignancies, the local and regional recurrences, metastases as well as secondary tumours were recorded. Besides this, the caregiver who requested the test leading to the diagnosis was determined (the surgeon or radiation oncologist versus other disciplines). A distinction was made between malignancies found by the yearly mammogram or as an outcome of a consultation.

Statistical analysis

To compare the actual performance of follow-up care with the recommendations in the national guideline, the Pearson χ^2 test was used. When the number of patients was too small, the Fisher's exact test was applied. To compare means, the Student's *t*-test was used. In case an observed mean was compared to expected means as indicated by the guideline, a one-sample *t*-test was conducted.

A one-way analysis of variance (ANOVA) was performed to determine if significant differences between means of follow-up consultations were found by subgroups of patient, tumour or treatment characteristics. For these comparisons several independent variables were used, age was collapsed into three categories (0–45, 46–60, 60+), stage in stage I, II, III or unknown, the different adjuvant treatments in either radiotherapy or none, chemotherapy or none and/or hormone therapy or none. Complaints were collapsed into 4 categories based on the total number of consultations in which a woman experienced complaints (0–25%, 25–50%, 50–75% or 75–100%). Both hospitals were also compared. The dependent variable was the number of follow-up consultations in the second through fifth year. Consequently, in this analysis only patients who completed the full five years of follow-up were used, since otherwise an average of these years could not be taken ($N = 142$).

In addition, a multiple linear regression analysis was performed to determine the independent association of factors that influence and predict the frequency of the follow-up consultations. The dependent variable was the number of follow-up consultations in the second through the fifth year. The independent variables were age, stage and the different adjuvant treatments. Both hospitals were also included. In modelling the multiple linear regression, variables were considered confounders and included in the model when the regression coefficient of the variable of interest changed