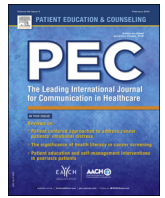




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Patient evaluation of breast cancer follow-up: A Danish survey

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ABSTRACT

Objective: The purpose of this study was to determine how age influences the degree to which patients with breast cancer feel comfortable with standard follow-up and to assess their satisfaction with the contact to health professionals.

Methods: Data was from a Danish population-based questionnaire survey from 2012 including adult cancer patients. 1120 patients with breast cancer returned the questionnaire (response rate: 73%). Age groups were decided before conducting analyses.

Results: Overall, patients with breast cancer evaluated the follow-up programme positively. However, in five of six items of interest, patients aged 40–49 and 50–59 years differed statistically significantly from patients ≥ 70 years, by being less comfortable with the follow-up, less satisfied with the health care professionals' ability to listen, and less satisfied with the health care professionals' answers. Satisfaction with the length of consultations, and the number of involved health care professionals were also lower in these age groups compared to patients ≥ 70 years.

Conclusion: Overall, satisfaction with follow-up was high, but considerable age-related variations were found.

Practice implications: The findings suggest a potential for improving the services provided for patients aged 40–59 years with breast cancer.

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1. Introduction

The incidence of breast cancer has increased for many years, but it seems to have reached a plateau in recent years [1,2]. During the same period, breast cancer survival has increased, primarily due to earlier detection and improved treatment. The 10-year overall survival rate for breast cancer is now above 75% in most European countries [3]. A consequence of the improved survival is that more individuals than ever before attend a breast cancer follow-up programme.

In Denmark, new follow-up programmes after cancer treatment are currently implemented based on the recognition that the former programmes were not based on evidence of effectiveness. Until recently, follow-up after breast cancer has consisted of regular consultations with a physician at the department of oncology once every sixth months for the first five years and once every 12 months for the following five years. All Danish women aged 50–69 years undergo screening mammography every second

year. Breast cancer patients outside this age range are offered clinical mammography at the choice of the clinician [4]. The purposes of breast cancer follow-up are threefold: early detection of recurrence and of new primary cancers, identification and treatment of therapy-related side effects and late morbidity, and provision of psychological support to the patients.

Incorporating patient reported experience measures (PREMs) in the evaluation of health care is important as patient experiences are now acknowledged as an important parameter of quality [5]. Dissatisfaction and distrust in health professionals may negatively affect patient compliance with both treatment and follow-up care and thereby negatively impact treatment results and recovery [6]. Several studies have investigated how breast cancer patients evaluate their treatment and follow-up. Among these, a French questionnaire study demonstrated that high patient satisfaction with the interpersonal skills of the physician, the information given, and follow-up in general, were factors associated with less 'unmet needs' for information and health care [7]. A qualitative study found that many breast cancer survivors complained about insufficient communication and lack of attention from the health care professionals [8]. Another qualitative study found that patients with breast cancer generally experienced the duration

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of hospital consultations as too short, resulting in dissatisfaction with the information provided about diagnosis, treatment and side effects [9].

Although much research focusing on breast cancer patients' evaluation of follow-up has included the impact of age, previous research has primarily focused on the oldest and the youngest age groups [10,11], although the middle-aged patients (40–59 years) represent a significant proportion of the patients with breast cancer.

Based on a nationwide Danish cross-sectional questionnaire survey the aim of this study was to investigate how age influences the patients' feelings of being comfortable in follow-up care and the patients' evaluation of the contact with the health care professionals. Compared to previous research, this study did not primarily focus on the oldest or the youngest breast cancer patients but analysed satisfaction across the age-continuum in pre-specified age strata.

2. Methods

2.1. Setting

The Danish health care system is tax-funded and provides free-of-charge access to general practitioners and hospitals for all Danish citizens. According to the Danish National Board of Health, all cancer treatment and follow-up should take place at public hospitals. Treatment and follow-up of breast cancer is based on nationally accepted guidelines developed by the Danish Breast Cancer Cooperative Group (DBCG) with the purpose of ensuring equal treatment and follow-up for all patients independent of socio-demographic characteristics. Treatment of breast cancer most often includes surgery in combination with radiotherapy, chemotherapy, endocrine therapy and in some cases targeted therapy. The follow-up programme used at the time of the survey is described in the introduction.

Linkage of registry data at the individual level is possible in Denmark by means of the unique personal identification number (CPR number), which is assigned to all Danish citizens. The Danish National Patient Register (NPR) contains information on all patient contacts in Danish hospitals.

2.2. Study population

This study was based on data from a Danish national cross-sectional population-based questionnaire survey focusing on cancer patients' needs, experiences and evaluations of the health services offered during treatment and follow-up. The survey took

place in 2012 and included adult Danish cancer patients aged 18 years or older who had been registered for the first time with a primary cancer diagnosis in the NPR during a 5-month period between 16 April 2010 and 15 September 2010. To be eligible for inclusion, patients had to live in Denmark, be alive at the time of invitation, and should not appear with "research protection" in the Danish Civil Registration (CPR) System (i.e. to the Danish authorities, the person had disclaimed contact by researchers). In the questionnaire patient reported their educational level and type of cancer treatment. This information was supplemented with data from the NPR (gender, age, cohabitation status, cancer type, and prior cancer diagnoses) and the CPR System (vital status and current postal address).

In the overall survey, 6914 cancer patients were sent a questionnaire and 4401 (64%) patients responded. In the present study, only persons with a breast cancer diagnosis (ICD-10 code C50.1-9) were included. Among the 1537 breast cancer patients who received a questionnaire, 1120 (73%) returned the questionnaire (Fig. 1).

2.3. Questionnaire

The 32-page questionnaire containing 121 items was developed to give a broad insight into the needs of cancer patients and their experiences with the Danish healthcare system during the period of treatment and follow-up [12]. A professional advisory panel critically assessed several versions of the questionnaire in order to adjust the terminology and the content. To ensure that the questionnaire captured the scientific intent and made sense to respondents, cognitive interviews with 14 patients, who differed with regard to age, gender, and cancer type were performed. The patients were asked to complete the questionnaire and explain their understanding of each item and substantiate their choice of response [13]. The analysis of the cognitive interviews led to further adjustments in the final version of the questionnaire.

The questionnaire and a prepaid return envelope were sent to each patient by postal mail in June 2012, i.e. approximately 2–2½ years after the patient had been diagnosed with cancer. Thus, all patients had completed primary treatment and had some experience with the follow-up programme. Non-respondents were sent a reminder, including the questionnaire and a prepaid return envelope, after approximately three weeks.

2.4. Variables

The independent variable of interest in this study was patient age. Before conducting analyses, patients were grouped into five

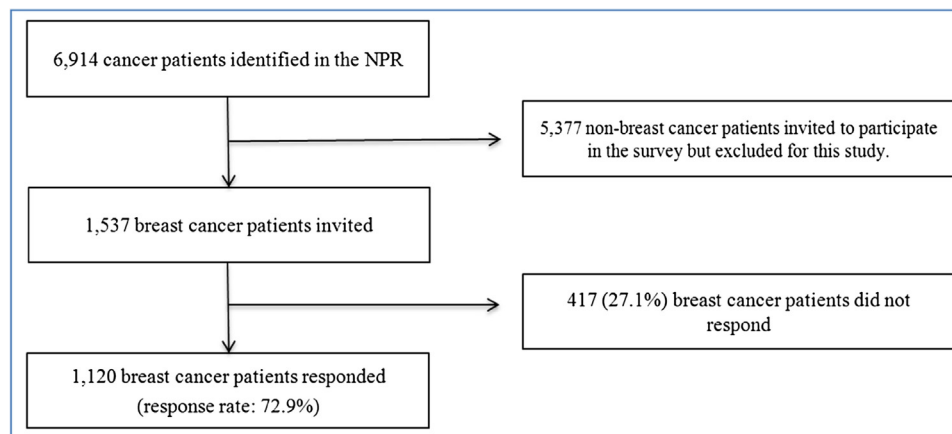


Fig. 1. Flowchart of patients identified in the NPR, reasons for exclusion, and breast cancer patients participating in the survey.

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