



Patients' beliefs about the aims of breast cancer follow-up: A qualitative study



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ABSTRACT

Objective: To explore patients' beliefs about the aims of breast cancer follow-up, and to compare these with the current literature on best practice for survivor care.

Study design: We reviewed the literature on breast cancer and interviewed 61 women with a history of early-stage breast cancer. By means of descriptive content analysis with qualitative and quantitative elements, the patients' verbatim responses were thematically and independently analysed by two researchers. Results were compared with current literature and breast cancer guidelines.

Results: When patients were asked to comment on what they thought the aims of breast cancer follow-up were, they most frequently mentioned 'detection of recurrence' and 'receiving reassurance', followed by 'receiving psychological support', and 'collecting data to evaluate care'. Some patients explicitly mentioned 'surveillance for metastatic disease' as an aim of follow-up. However, some patients believed that breast cancer could not recur after 2–5 years of follow-up, and that recurrences could not develop directly after or between follow-up appointments. In relation to follow-up appointments, some patients experienced anxiety, while others felt it made them confront their breast cancer history.

Conclusions: Patients' beliefs are often not in line with guidelines. Educating patients about the aims of follow-up, and the evidence underlying it, might be important, in part to make patients' expectations more realistic.

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1. Introduction

Breast cancer is the most common malignancy and the leading cause of cancer-related death among women worldwide, with the incidence continuing to increase in many countries [1]. In this contribution we reviewed the literature on breast cancer epidemiology, treatment, related side-effects, and follow-up. In addition, the results of a qualitative study, in which patients' beliefs about the aims of breast cancer were explored, are reported.

1.1. Breast cancer epidemiology

In The Netherlands, the increased incidence has been attributed to population ageing, the implementation of a national screening programme, and unfavourable changes in risk factors related to reproduction and lifestyle [2]. Next to the increased incidence,

the survival rates of women with breast cancer have increased in many countries because of improved staging and treatment, and because of early detection by mammography, though the effect of the latter can probably partly explained by lead and length time bias [1]. Indeed, the 5-year relative survival rate in The Netherlands increased from 77% for women diagnosed in 1989–1993 to 87% for women diagnosed in 2008–2012 [3]. The increased incidence and improved survival have resulted in more women are entering into breast cancer survivorship.

1.2. Treatment

After being diagnosed with breast cancer, 90%–95% of patients show no evidence of distant metastasis (stage IV) [4], and are treated with curative intent [4–7]. Patients with stage I–II breast carcinomas undergo either breast conserving therapy (BCT; including lumpectomy and adjuvant radiation therapy) or mastectomy [5]. Furthermore, adjuvant systemic therapy may be offered, including chemotherapy, hormonal therapy, or targeted therapy [5]. Neo-adjuvant systemic therapy, followed by BCT or mas-

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tectomy, is recommended for stage III invasive carcinomas with locoregional metastasis. In Western countries, breast cancer is treated by multidisciplinary teams including surgeons, radiologists, pathologists, medical oncologists, radiation oncologists, and breast care nurses [8,9].

1.3. Treatment-related side effects

Several treatment-related side effects have been reported in the literature. Common symptoms and problems after breast cancer treatment are menopausal symptoms, sexual dysfunction, cognitive dysfunction, fatigue, pain, weight gain, arm swelling, and psychological distress [10,11]. Moreover, there are suggestions that patients with a history of breast cancer might have an increased risk of cardiovascular disease, hypothyroidism, and osteoporosis [10,12]. Studies have shown that breast cancer survivors frequently have greater numbers of chronic comorbidities than matched non-cancer controls [13]. Although most patients with a history of breast cancer report a good quality of life, they may experience specific symptoms or problems related to breast cancer and its treatment [14,15]. In The Netherlands, management of these problems is the responsibility of both breast cancer specialists and general practitioners (GPs) [16].

1.4. Follow-up

Patients with a history of breast cancer are at an increased risk for locoregional recurrence and contralateral breast carcinoma, and this risk persists for more than 20 years [10]. Thus, follow-up has several aims, according to evidence based (inter)national guidelines (ESMO, Dutch guideline, ASCO and NICE) [4–7], including: to detect locoregional recurrence early [5,17], to provide psychological support [5,17], to monitor treatment-related side effects [5,17], and to collect data for the evaluation of care [5] (Table 2). Surveillance mammography is recommended to detect both locoregional recurrence and contralateral breast carcinoma early [10]. However, additional routine investigations (e.g., blood tests, chest X-rays, and MRI) are not recommended for the detection of asymptomatic metastatic disease because early detection does not improve survival rates from metastatic disease [10,17]. Most guidelines also recommend follow-up visits for history and examination [5–7], although the contribution of this to the early detection of recurrences is uncertain given that most relapses are detected either by patients themselves or by mammography [18].

1.5. Study aim

Two quantitative surveys on needs and preferences for screening in follow-up revealed that patients with a history of breast cancer have high expectations of the potential benefits. For example, patients are often willing to undergo frequent additional investigations with the expectation of having a greater chance of survival when distant metastases are detected at an early stage [19,20]. Thus, women appear to lack realistic information about the potential benefits of follow-up [19], which might contribute to continued follow-up years after treatment, even when no clinical benefit remains. To provide a deeper understanding of patients' beliefs of the potential benefits and disadvantages of follow-up, we performed an additional analysis of earlier collected data [21].

2. Methods

2.1. Patients

In an already published qualitative study, we described the preferences for follow-up in primary care vs. secondary care among 70

Table 1
Characteristics of the patients included in the analysis (n = 61).

Characteristic	N (%), unless otherwise stated
Age at diagnosis, years	median 55.4, range 27–83
<40	7 (11)
40–50	11 (18)
50–60	22 (36)
60–70	15 (25)
≥70	6 (10)
Education	
Primary school/GCSE (lower educated)	13 (21)
GCSE	19 (31)
A-levels	9 (15)
College/university	20 (33)
Breast cancer T stage	
Tis/T1	38 (64)
T2/T3/T4	21 (36)
Unknown	2
Breast cancer N stage	
N0	44 (72)
N+	17 (28)
Surgery	
Lumpectomy	34 (56)
With radiotherapy	33 (97)
Mastectomy	27 (44)
With radiotherapy	6 (22)
Systemic treatment	
None	10 (16)
Chemotherapy	31 (51)
Endocrine therapy	15 (25)
Chemotherapy + endocrine therapy	5 (8)
Recurrent breast cancer during follow-up	
Locoregional	3 (5)
Contralateral	1 (2)
Age at time of interview, years	median 63, range 34–88
Time since diagnosis, years	median 7, range 1–23
3	3 (5)
2–5	19 (31)
5–10	23 (38)
≥ 10	16 (26)

GCSE: General Certificate of Secondary Education.

women with a history of early breast cancer [21]. Female patients with a history of early-stage breast cancer were invited by their GP. Details regarding the study setting, patient recruitment, interview guide development, and data collection are described in the original report [21]. For 61 of these women, we asked what they believed the potential benefits and disadvantages of follow-up visits were. This topic was discussed in depth, with no suggestions made by the interviewer.

2.2. Data analysis

Patients' responses were independently coded by two researchers using descriptive content analysis [22]. Themes were identified and the researchers discussed any discrepancies until consensus was reached. Given the large amount of interviewed patients, descriptive statistics were applied to describe the patients' characteristics and the perceptions of follow-up. Informed consent was obtained prior to the interview, participants having received an invitation letter and information letter.

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