The role of the general practitioner during treatment and follow-up of patients with breast cancer
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CHAPTER 1
General introduction
Cancer of the breast is a heterogeneous disease and can be classified in several ways, for example based on its histological type\textsuperscript{1} and the anatomical extent of the disease.\textsuperscript{2} The two most common histological subtypes of invasive breast cancer are ductal and lobular carcinomas, accounting for approximately 75\% and 15\% of all invasive carcinomas.\textsuperscript{1,3} Other subtypes may include: mixed ductal/lobular, mucinous, comedo, inflammatory, tubular, medullary, and papillary carcinomas.\textsuperscript{1} Ductal carcinoma in situ is an established precursor of invasive breast cancer,\textsuperscript{4} while lobular carcinoma in situ and atypical lobular hyperplasia are risk factors for invasive breast cancer, and may be precursors as well.\textsuperscript{5}

The anatomical extent of breast cancer is determined by using the Tumor Node Metastasis (TNM) staging system of the International Union for Cancer Control.\textsuperscript{2,6} Classification is based on tumour type (in situ or invasive) and size (T), absence or presence of the disease into the regional regional lymph nodes (N), and absence or presence of distant metastasis (M).\textsuperscript{2} The main stage groups include: stage 0 describing in situ carcinomas, stage I-III describing invasive carcinomas within the breast and the regional regional lymph nodes, and stage IV describing invasive carcinomas with distant metastasis.\textsuperscript{6,7}

Breast cancer is the most common malignancy and the leading cause of cancer-related death among both women worldwide\textsuperscript{8} and European women.\textsuperscript{9} In 2011, about 14,000 Dutch women were newly diagnosed with an invasive breast carcinoma. About 2,000 Dutch women were diagnosed with a non-invasive/in situ carcinoma in this year.\textsuperscript{10} Incidence rates of female breast cancer have increased in many countries.\textsuperscript{8,9} In the Netherlands, the increase in breast cancer incidence can be attributed to the ageing of the population, the implementation of the national screening programme, and unfavourable changes in reproductive and lifestyle-related risk factors over the years.\textsuperscript{11} These risk factors may include: a lower...
age at menarche, a higher age of the mother at first childbirth, a shorter duration/lack of breastfeeding in combination with a lower parity, a higher age at menopause, the use of hormone replacement therapy, obesity, physical inactivity, smoking, and alcohol consumption.

Survival rates of female breast cancer have increased in many countries as a result of early detection by mammography and improved treatment. In the Netherlands, the 5-year relative survival rate increased from 77% for women diagnosed in 1989-1993 to 86% for women diagnosed in 2006-2010. Together with the increased incidence rates, the improved survival rates have resulted in an increase in the number of women with a history of breast cancer. In the Netherlands, the absolute 10-year prevalence of female breast cancer increased from 88,938 women in 2007 to 101,747 women in 2012. It has been estimated that this 10-year prevalence will increase to about 140,000 women in 2020. In a Dutch general practice with an average list size of 2350 patients, two women are newly diagnosed with breast cancer each year. Moreover, there are about 15-17 women with a history of breast cancer in an average general practice.

**TREATMENT AND RELATED SIDE-EFFECTS**

In the Netherlands and other countries in Europe, breast cancer is treated by multidisciplinary teams with surgeons, radiologists, pathologists, medical oncologists, radiation oncologists, and breast care nurses as core members. After being diagnosed with breast cancer, 90-95% of patients show no evidence of distant metastasis (stage IV) and are treated with curative intent. Patients with ductal carcinoma in situ and patients with stage I-II invasive breast carcinomas undergo either breast conserving therapy (BCT; including lumpectomy and adjuvant radiation therapy) or mastectomy. Furthermore, adjuvant systemic therapy may be offered, including chemotherapy, hormonal therapy, and/or immunotherapy (trastuzumab). Neo-adjuvant systemic therapy, followed by BCT or mastectomy is recommended for stage III invasive carcinomas with loco-regional metastasis. This may also be considered for stage II invasive carcinomas to reduce the size of the tumour enough to allow BCT (downstaging).
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, and arm swelling.\textsuperscript{24,36} Psychological distress, anxiety, and depression are also common.\textsuperscript{24,36} Moreover, patients with a history of breast cancer have an increased risk for cardiovascular diseases, hypothyroidism, and osteoporosis.\textsuperscript{24,36,37} They may suffer from diabetes and other chronic comorbid conditions as well.\textsuperscript{28,29} Treatment-related side effects, negative psychosocial outcomes, and comorbid conditions have been associated with a worse health-related quality of life\textsuperscript{27,38} and lower rates of adherence to adjuvant endocrine therapy.\textsuperscript{38-40} Management of these side effects, outcomes and conditions can be either the responsibility of a breast cancer specialist or a primary care physician, like a general practitioner (GP). With its capacity for multidimensional care, general practice is regarded as well placed to play a leading role in improving quality of life and other outcomes in patients with cancer.\textsuperscript{41,42} However, a better understanding of the role of primary care during cancer treatment and thereafter is needed.\textsuperscript{42,43}

**SURVIVORSHIP CARE AND FOLLOW-UP**

Patients with a history of breast cancer are at risk of loco-regional recurrences and contralateral breast carcinomas for more than 20 years.\textsuperscript{24} Although most of them will report a good quality of life over time, they may experience specific symptoms or problems related to breast cancer and its treatment.\textsuperscript{25-27} Studies have shown that breast cancer survivors frequently have more chronic comorbid conditions than matched non-cancer controls.\textsuperscript{28,29} Therefore, they do need cancer surveillance, cancer screening, and general medical care for comorbid conditions and preventive health issues.\textsuperscript{30} Until now, it is unclear which care provider - breast cancer specialists, primary care physicians, nurses, or a combination of these - should be responsible for what component of survivorship care.\textsuperscript{30,31}

The aims of breast cancer follow-up are to detect loco-regional recurrenc-
es at an early stage, to monitor treatment-related side effects, to provide psychological support, and to collect data for evaluation of care. Surveillance mammography is recommended to detect both locoregional recurrences and contralateral breast carcinomas at an early stage. Additional investigations for surveillance of metastatic disease (like blood tests, chest X-ray, and MRI) are not recommended, since these investigations do not lead to improved survival of patients with a history of breast cancer. Most guidelines also recommend follow-up visits for history taking and physical examination, although the contribution of physical examination to the early detection of recurrences is uncertain since the majority of relapses are detected by patients themselves or by mammography.

Guidelines do vary not only with respect to frequency and duration of follow-up visits but also with respect to which care provider should perform follow-up, as the optimum approach is unknown. Two randomised clinical trials, comparing follow-up provided by a GP or family physician to specialist follow-up, found no differences in measures of health-related quality of life, anxiety and depression between both groups. In the first trial, patients in the GP group were more satisfied with follow-up than patients in the specialist group. Moreover, costs were lower in the GP group, despite more frequent and longer follow-up visits. However, patient numbers were too small or follow-up duration was too short to evaluate the impact on survival rates.

**THE ROLE OF THE GENERAL PRACTITIONER**

At the time of starting this PhD project (May, 2008), Dutch GPs did not play a formal role in the care of women undergoing breast cancer treatment and follow-up. Just as GPs in countries like Australia and the United Kingdom, they were formally involved in early detection of cancer and in symptom control during the palliative/terminal stage. It was believed that GPs lost touch with their patients during cancer treatment and that they stayed on the periphery of cancer care until patients reached the palliative stage. Since September 2008, Dutch GPs have a coordinating role.
role in the long-term follow-up (>5 years) of women aged >60 years who had undergone BCT. Due to positioning and evaluation problems associated with the operated and irradiated breast, these patients cannot be referred to the National Screening programme for biennial mammography. Therefore, discharge to their GP for annual physical examination and biennial mammographic follow-up in the hospital - where the first five years of follow-up took place - is recommended.

In May 2011, a greater role for GPs and other primary care professionals in integrated cancer care was advocated by the Signalling Committee Cancer of the Dutch Cancer Society, based on the expected increase in the prevalence of cancer survivors and the accompanying burden on the Dutch health care system. Furthermore, this working group has recommended that GPs should become responsible for cancer follow-up (unless there is convincing evidence that specialists should play a major part in this follow-up). To incorporate new responsibilities of GPs into existing primary healthcare delivery, it is important to know to what extent they are already involved in care for women undergoing breast cancer treatment and follow-up. Furthermore, shifting breast cancer follow-up to the primary care setting has to be accepted by all parties involved, including GPs, patients, and specialists.

**AIM OF THIS THESIS**

The overall aim of this thesis is to describe the role of Dutch GPs during the breast cancer treatment phase [defined as the first year since diagnosis] and the follow-up phase [defined as the period starting one year post-diagnosis]. Moreover, this thesis explores perspectives of GPs and patients regarding the transfer of breast cancer follow-up to the primary care setting Specific objectives of the studies presented in this thesis are:

1. (a) To explore primary health care use among patients and (b) to investigate specific characteristics associated with this healthcare use [Chapter 2 and 3].
2. (a) To describe the discharge of patients to primary care by specialists, at the end of hospital-based follow-up and (b) to explore experiences
and views of GPs regarding transfer of follow-up to the primary care setting [Chapter 4].

3. (a) To explore patients’ preferences for follow-up in primary care versus secondary care and (b) to gain a deeper understanding of patients’ perceptions of the aims of follow-up [Chapter 5 and 6].

**THESIS OUTLINE**

In the first part of this thesis, results of two longitudinal studies on primary health care use of patients during the breast cancer treatment phase [Chapter 2] and the follow-up phase [Chapter 3] are presented. The first part also includes a letter to the editor, commenting on the interpretation of findings concerning primary health use of breast cancer survivors [§ 3.1]. The second part of this thesis describes the results of a quantitative mail survey exploring GPs’ experiences and perspectives regarding primary care-based follow-up [Chapter 4]. In the third part, results of a qualitative study exploring patients’ views on primary care-based vs. specialist follow-up [Chapter 5] and the aims of follow-up [Chapter 6] are reported. This thesis ends with a general discussion [Chapter 7] of main findings, methodological considerations and implications for clinical practice, education, and future research.
PART I
Primary health care use during treatment and follow-up

Chapter 2 Role of the general practitioner during the active breast cancer treatment phase: an analysis of health care use

Chapter 3 Increased primary healthcare utilisation among women with a history of breast cancer

§ 3.1 Do breast cancer survivors visit their General Practitioner for psychological problems?