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Quality of care: Distress, health care use and needs of women with breast cancer

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Chapter 1

Introduction
Breast cancer

Breast cancer is the most frequently diagnosed cancer among women worldwide \(^1\). In the Netherlands, a woman’s risk of having breast cancer at some point in life is 12-13\(^\%\) \(^2\). In 2010, when this study started, approximately 13,300 Dutch women received a breast cancer diagnosis. The breast cancer incidence is rising, due to an aging population, the use of early detection programs, and an increase in risk factors such as having children later in life and use of combined hormone therapy after menopause. Fortunately, the breast cancer mortality rate is decreasing at the same time, thanks to early detection and the accessibility of more successful treatments \(^3\). The current national relative survival rate is 87\% at 5 years after diagnosis, and 77\% after 10 years \(^4\).

The recommended type(s) of treatment after a breast cancer diagnosis depend on patient and tumor characteristics. Almost all women with an early stage tumor receive breast-conserving (lumpectomy) or ablative (mastectomy) surgery. Additionally, they may receive radio-, chemo-, hormonal and/or immunotherapy – as single or combination therapy – to reduce the risk of recurrence. After active treatment, patients regularly visit their surgical oncologist, medical oncologist, radiotherapist or cancer nurse for follow up visits and after care. These visits enable early detection of local recurrence or a second tumor, and provision of treatment-related and psychosocial support. Even though treatment of breast cancer in the Netherlands is protocolized, the standard duration and frequency of follow-up visits may vary among hospitals.
Distress

Most women, naturally, experience more or less distress due to having breast cancer and its consequences. Distress is defined as ‘a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its symptoms and its physical treatment’ \(^5\). Approximately one third of all women with breast cancer will develop a clinically relevant level of distress \(^6-9\) (see also \(^{10}\)), which has been associated with lower treatment-adherence, poorer clinical and psychosocial outcomes, and less satisfaction with medical care \(^{11-16}\). Fortunately, most of the time, having clinical distress is temporary \(^{17-22}\). However, some women will develop enduring, heightened, distress. They are at risk of having poorer psychosocial outcomes up to six years later \(^{15}\).

A widespread practice to ensure detection, exploration, and treatment of distress, is to routinely screen patients with the Distress Thermometer and accompanying Problem List \(^5\). This self-report questionnaire assesses cancer patients’ distress level and distress-related problems, along with their wish for referral to professional care. Practitioners may benefit from knowing which patients have a higher risk of developing clinically relevant distress. As for yet, younger age \(^{23-25}\) (but see also \(^{26}\)), more extensive surgery \(^{25}\), treatment with surgery, chemotherapy and radiotherapy \(^{26}\), a prior diagnosis of depression \(^{27}\), poorer quality of life \(^{26,28,29}\), and experiencing fatigue \(^{26}\) have been found to be associated with higher or clinical distress in previous studies with the Distress Thermometer. However, to enable timely identification of clinical distress, more research is needed.
Firstly, most of the previous findings were based on studies with a cross-sectional design. There is a need for studies that prospectively examine which women with breast cancer will, generally, develop clinical distress, and in particular, enduring clinical distress, as measured with the Distress Thermometer (see also 21).

Secondly, there is a need for innovative aids that can facilitate physician–patient communication about distress with less text-literate patients. One original approach encompasses use of graphic novels during consultations 30 (see also 31). Graphic novels combine prose and pictures in a comic-book narrative (cf. 32). This combination may lead to better cognitive understanding, thanks to simultaneous activation of text processing and visual image areas in the brain 33,34. There are accounts of medical health-care providers who would recommend a graphic novel about breast cancer to their patients 35 (see also http://knopfdoubleday.com/book/107478/cancer-vixen/). However, up to now, we have little insight in the extent to which a graphic novel about breast cancer depicts the full range of possible distress-related problems.

**Health care use**

A diagnosis of breast cancer generally leads to increased health care use in the long-term 36-42. For example, a study in Denmark found that five to fifteen years after surgery, more breast cancer survivors (n=1,316) than women from the general population (n=4,865) were hospitalized or paid a visit to a medical or paramedical specialist 39. A North American study demonstrated that cancer survivors (n=1,111, of which 42% breast cancer survivors) also pay more mental health visits than controls without a history of cancer (n=4,444, matched on age, sex, and clinic location) 43. A number of studies examined predictors of increased care use with
regard to varying types of care (e.g., 37,42,44,45). Practitioners may benefit from the resulting insights by being especially watchful of those women at risk of using, and thus needing, more care services. However, to enable tailored care, more research is needed.

Firstly, the studies that examined predictors of care use among women with breast cancer, sometimes report contradictory findings. A systematic review is needed to identify the most relevant predictors of hospitalization, and medical, paramedical, and psychosocial care per phase in the disease trajectory. Consequently, tailored and cost-effective interventions may target the most relevant risk factors at the appropriate time.

Secondly, the available information on health care practices of women with breast cancer and predictors thereof, does not convey whether women find that the amount of received care is sufficient. Thus, there is a need for studies that examine women’s care use, more specifically, their use of medical, paramedical, psychosocial, and supplementary care (e.g., home care), along with their need for additional services.

Thirdly, health care use encompasses a wide range of care services. A large number of women with breast cancer (45%) also use complementary and alternative care (CAM) 46,47. Based on the CAM Healthcare Model (adapted from 48), it is possible that women who use self-directed (self-help) CAM have different characteristics than women who use provider-directed (guided) CAM. However, as for yet, this has not been examined. Additionally, we do not know how many women with breast cancer use self-directed and provider-directed CAM over time, and for what reasons.

Finally, it is less recognized that women with breast cancer may also suffer from dental problems, primarily after adjuvant systemic therapy. Problems may become severe enough to interfere with scheduled treatments, which in turn may
lead to higher health care use and costs \textsuperscript{49-51}. Visits to the dentist prior to and, if needed, during treatment may prevent or restrict the range and severity of oral problems (e.g., \textsuperscript{52}, see also \textsuperscript{53}). Yet, to date, little is known about women with breast cancer’s actual dental care use compared to women from the general population. Furthermore, knowledge of prospective predictors of women’s dental care use, and of women’s need for more dental care services is lacking. Practitioners thus have limited insight into whether and which women with breast cancer visit their dentist, and whether the women think more use of dental care services is warranted.

**Unmet health care needs**

Despite a large quantity of available care resources, a considerable proportion of women with breast cancer report unmet needs to cope with their problems. More specifically, 20\% of women with breast cancer report at least one moderate or high unmet need across varying need domains. The prevalence of specific needs, especially informational needs, may reach up to 70\% \textsuperscript{54}. Women’s unmet needs are generally highest during treatment. However, a greater number of women are likely to report unmet needs in the post-treatment phase \textsuperscript{55}.

Oncologists and cancer nurses can profit from knowing which women with breast cancer are at risk of having unmet needs. Based on previous studies, we know that younger women, with an advanced disease stage, who are treated with chemotherapy, and who experience greater symptom burden or higher levels of distress should be monitored more closely than others \textsuperscript{54}. However, to enable timely and tailored care, more research is needed.
Firstly, few studies prospectively examined risk factors of unmet needs in the post-treatment phase – when the prevalence of needs is highest\(^{56-58}\). Secondly and most importantly, needs, by definition, refer to problems that require additional care resources or an action to obtain optimal well-being\(^{54,55,59}\). This implies that received care resources partly determine one’s level of unmet need. Yet, the interplay between risk factors – including distress –, care use and unmet care need domains of women with breast cancer has not yet been examined.

**Aims of this thesis**

The overall aims of this thesis are to:

a. examine enduring distress and its predictors in women with breast cancer (chapter 2);

b. examine the extent to which distress-related problems are portrayed in a graphic novel about breast cancer (chapter 3);

c. examine health care use and additional needs (with regard to medical, paramedical, psychosocial, supplementary, CAM, and dental care services), and predictors of care use in women with breast cancer around the completion of treatment and post-treatment (chapters 4 to 7);

d. examine predictors of unmet care needs of women with breast cancer in the post-treatment phase, including distress and varying types of health care use (chapter 8).
Thesis outline

Based on the examined topics, the thesis is divided into three parts, namely part 1: Distress (chapters 2 and 3), part 2: Health care use (chapters 4 to 7), and part 3: Unmet health care needs (chapter 8).

In chapter 2 we examine the prevalence of enduring clinical distress, distress-related problems, and a subsequent wish for referral among women with breast cancer. We also examine sociodemographic, clinical, and psychosocial predictors of enduring clinical distress. The findings are based on the Pink Diamond study, a prospective, nationwide study among women with primary breast cancer (Diamond being an acronym for DIstress Assessment Mammacarcinoma for Optimal Needs-oriented Delivery of care). The study addresses two time points: 6 months post-diagnosis, and 9 months later when most patients have had their primary surgery and have completed adjuvant radio- and/or chemotherapy. Enduring clinical distress is defined as a clinical level of self-reported distress at both time points. The included possible predictors are assessed by self-report at 6 months post-diagnosis. Clinical data are partly retrieved from medical records.

In chapter 3 we investigate which distress-related problems are depicted in a graphic novel about breast cancer, using qualitative content analysis. We provide examples of the manner in which frequently depicted problems are portrayed.

In chapter 4 we perform a systematic review to determine which characteristics of women with breast cancer are consistently associated with (more frequent) health care use. We also investigate whether these characteristics differ per phase in the disease trajectory (i.e., health care use in the treatment, post-treatment, or survivorship phase). The care types of interest are hospitalization, and curative medical, psychosocial, and paramedical health care.
Sociodemographic, enabling (e.g., income), clinical and health related, and psychosocial predictors are examined.

In *chapter 5* we prospectively investigate the prevalence of varying types of health care use and needs of women with breast cancer (i.e., use of, and additional needs for medical, paramedical, psychosocial, and supplementary care services). The findings are based on the Pink Diamond study. Respondents’ care use and needs are examined at 6 and 15 months post-diagnosis.

Subsequently, in *chapter 6*, we examine the prevalence of dental care use and needs of women with breast cancer over time. We compare their prevalence of use with that of the general population to determine possible underutilization. Furthermore, we examine sociodemographic, clinical, and psychosocial predictors of dental care use. The findings are based on the Pink Diamond study.

In *chapter 7* we examine stability of use of provider-directed and self-directed CAM among women with breast cancer. We additionally examine reasons for, and sociodemographic, clinical, and psychosocial predictors of provider-directed and self-directed CAM use. The data used in this study are part of a larger dataset that was collected in a multicenter, observational Dutch study with six assessments during the first year after diagnosis. CAM use and reasons for CAM use in this study were assessed by self-report immediately after adjuvant chemo- or radiotherapy, and six months later. The included possible sociodemographic and psychosocial predictors of CAM use were assessed by self-report immediately after adjuvant therapy or surgery. Clinical data were retrieved from medical records.

In *chapter 8* we examine the extent to which a number of risk factors, as measured 6 months post-diagnosis, predict health care use and needs of women with breast cancer at 15 months post-diagnosis. Distress is included as one of the
risk factors, and as a potential mediator (Figure 1). The findings are based on the Pink Diamond study. Our hypothesis is that (a) sociodemographic and clinical variables will predict more frequent health care use and higher levels of unmet needs, partly through distress; (b) a higher level of distress will also directly predict more frequent health care use and higher levels of unmet needs; and (c) more frequent health care use will be associated with lower levels of remaining unmet needs.

In chapter 9 a summary of the thesis is provided.
Figure 1. Model of associations between predictors, distress, and care use and unmet needs over time.

6 months post-diagnosis

**Sociodemographic and clinical factors**
- age, educational level, type of health insurance,
- cancer stage, type of surgery, radiotherapy, chemotherapy,
- hormonal therapy, comorbidity,
- psychosocial treatment before diagnosis

Distress

15 months post-diagnosis

**Health care use**
- medical care use
- psychosocial care use
- paramedical care use
- supplementary service use

**Unmet health care needs**
- physical and daily living needs
- patient care and support needs
  - psychological needs
  - sexuality needs
- system-related and informational needs
- breast cancer specific needs
References


