Chapter 1

Introduction
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1.1 Introduction

‘As our colleagues in medicine explore new kingdoms of life-saving technology, we often find psychological wrecks in their wake. We can help to reconstitute these people. Our interventions can be life-saving.’ Psychiatrist TP Hackett (1977) in the early days of psycho-oncology

Despite major advances in cancer detection and treatment, a cancer diagnosis is threatening and can abruptly change people’s life. Having cancer today is however in various ways different from having cancer a couple of decades ago (Breitbart & Chochinov, 1998; Holland, 2002; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). At the beginning of the 20th century, cancer was a taboo subject, surrounded by silence, shame and guilt. Knowledge about the causes and cure of the disease was scarce and, consequently, a cancer diagnosis often resulted in death. In the 1930s, research in cancer treatment was initiated. Owing to the introduction of chemotherapy and more effective surgery and radiation, survival rates gradually increased. Slowly, an interest in the long term effects of cancer treatment emerged and more attention was paid to patients rights, for example their right to be informed about their diagnosis and to have a role in treatment decisions. In the mid-1970s, when increasing numbers of cancer survivors publicly expressed their successful outcomes, the stigma of cancer debated and people started to share their experiences. Cancer ‘came out of the closet’ (Holland, 2002). In this period, researchers also started to investigate the psychological dimension of cancer. In the last three decades, this area of research - named psycho-oncology - has rapidly evolved and has increased our understanding of psychological issues related to cancer diagnosis, treatment and survival of cancer.

Ever since the early days of psycho-oncology, the psychological well-being of women with breast cancer proved to be a popular research topic. A quick search in Psychinfo results in approximately 1500 papers on psychological issues in breast cancer (10 papers before 1980, 121 in 1981–1990, 436 in 1991–2000 and 892 in 2001-2009). Regarding the course of well-being over the first year after diagnosis, we now know that the first months are generally most stressful and that well-being gradually improves thereafter (Millar, Purushotham, McLatchie, George, & Murray, 2005; Stanton, Danoff-Burg, & Huggins, 2002). Yet, not much is known about how distinct stages in the first year, characterized by different types of stressors, each trigger different kind of emotions. Moreover, a gradual recovery in well-being over time might characterize the adjustment process of some, but not of all patients. By addressing these more refined questions with a carefully chosen research design, the current thesis aims to add to the existing knowledge on psychological well-being in women with breast cancer.
A related topic that has always intrigued both researchers and clinicians is why some people cope successfully with cancer while others have more problems coming to terms with the disease. By now, we know that differences in disease severity do not explain well why some patients experience psychological problems while others do not (Bardwell et al., 2006). Personal characteristics, like an optimistic personality, seem to play a far more important role (Reich, Lesur, & Perdrizet-Chevallier, 2008). One personal characteristic that has received considerable attention in studies on the adjustment to cancer is perceived personal control. Perceived personal control refers to people’s belief regarding the extent to which they are able to control or influence outcomes (Pearlin & Schooler, 1978). Despite the uncertain and uncontrollable nature of cancer, a sense of personal control is generally believed to be an important personal resource for successful psychological adjustment (Taylor et al., 1984; Helgeson et al., 2004). Yet, not much is known about why and when a sense of personal control is adaptive. This thesis aims to gain more insight in the role of perceived personal control in the adjustment process after a breast cancer diagnosis.

Hence, this thesis is about psychological well-being and perceived personal control in women with breast cancer. In this first introductory chapter, some numbers on the incidence of breast cancer and the organization of breast care in the Netherlands will be presented, as well as the various treatment options available after a breast cancer diagnosis (1.2). Moreover, an overview of each of the studies presented in this thesis will be provided in two paragraphs; one about psychological well-being in women with breast cancer (1.3) and one about the role of perceived personal control in the adjustment process (1.4). Box 1.1 presents more details about the procedure, sample and design of the study.

1.2 Breast cancer diagnosis and treatment

‘Zodra men in de wereld komt waar borsten mamma’s worden genoemd, is er meestal wat mis.’
Kluun, October Breast Cancer Awareness Month 2005

Incidence and survival
In the Netherlands, one in eight women is diagnosed with breast cancer at some point in life. In 2005, the year this study started, over 12,000 Dutch women were diagnosed with a malignant tumor in the breast (Comprehensive Cancer Center the Netherlands, Cancer Registry). Because of the introduction of screening programs, the ageing population and an increase in risk factors in the Western world, the incidence of breast cancer is rising. Fortunately, due to earlier diagnosis and more effective treatment, survival has increased as well (Signaleringscommissie Kanker, 2004). Currently, the relative five year survival rate is 85%.
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Diagnosis
When a suspicion of breast cancer is raised - either by women themselves, the
general practitioner or through screening - women are referred to the hospital for
further diagnostic testing. In most Dutch hospitals, care for women with breast
disease is organized in multidisciplinary breast care teams, consisting of surgeons,
radiologists, pathologists, radiotherapists, oncologists and breast care nurses. The
multidisciplinary character of the team enables a fast diagnosis. Approximately
one out of three women visiting a breast clinic (mammapoli) turns out to have a
malignant breast tumor (i.e., breast cancer).

Treatment and follow-up
After diagnosis, the multidisciplinary team discusses the treatment protocol.
Almost all women diagnosed with breast cancer undergo surgery within several
weeks after diagnosis. This surgery can be either breast conserving (lumpectomy)
or ablative (mastectomy), depending on the size, grade and spread of the tumor.
Depending on the presence of cancer cells in the sentinel lymph node, a lymph
node dissection is performed. Breast surgery changes the shape or completely
removes the affected breast. Surgery can cause pain, numbness and the loss of
function of the upper-body and arm. A disturbing long term effect of a lymph
node dissection is lymphedema, the swelling of the arm due to fluid retention.

After one or more surgeries, radiotherapy, chemotherapy, hormone and
immune therapy are prescribed separately or in combination, again depending
on the characteristics of the tumor. Radiotherapy is a fixed component of a breast
conserving treatment protocol, but can also be prescribed adjuvantly after a
mastectomy. Usually radiotherapy starts several weeks after surgery and implies
25-35 radiation sessions over a period of 5-7 weeks. Most frequent side effects
of radiotherapy include a loss of energy and skin problems. Chemotherapy,
the administration of toxic medications that are particularly damaging to cancer cells,
is prescribed when the tumor is large, aggressive or when the cancer has spread
to the lymph nodes. Chemotherapy usually consists of 6-8 courses administered
every 2-3 weeks. Side effects are rather intrusive and include hair loss, nausea,
vomiting, fatigue and sometimes cognitive impairments. Hormone therapy is
prescribed when the tumor has unfavorable prognostic characteristics (size, grade,
nodes) and turns out to be sensitive to the female hormone estrogen. Hormone
treatment can take several forms, i.e. medication (tamoxifen and aromatase
inhibitors) or an ovarian ablation. Often hormone therapy implies that women
need to take pills daily for several years. Side effects of hormone treatment can
include an early menopause or complaints related to menopause, like hot flashes
and mood swings. Lastly, a relatively novel treatment modality is the prescription
of immune therapy. Immune therapy (trastuzumab) is prescribed when the tumor
contains more than the usual amount of a growth factor receptor (her2neu over-
expression). It is administered in the hospital once every three weeks for a period
of one year. It can cause an ill feeling and, in a few cases, might result in heart
problems.
After the completion of treatment women are monitored for several years. During these follow-up consultations, the patient is checked for local recurrence or metastases. Side effects of treatment as well as the psychosocial situation of patients are discussed.

In sum
This short overview of the illness trajectory clearly demonstrates that diagnosis is certainly not the only adverse event, but that breast cancer involves many additional potential stressors, ranging from treatment and it's side effects to learning to live with the risk of recurrence. This thesis will examine how the different phases in the illness trajectory in the first year after diagnosis, each characterized by distinct stressors, affect the psychological well-being of women with breast cancer. The overview also demonstrates that the period after a breast cancer diagnosis is characterized by a high degree of uncertainty and unpredictability. The role of patients' sense of personal control in these rather uncontrollable circumstances constitutes the second theme of this thesis.

1.3 Psychological well-being in the first year after a breast cancer diagnosis

Breast cancer can trigger various negative emotions, like anxiety or sadness. To a certain degree, some of these emotions might have an adaptive function on the short term, e.g., treatment anxiety might activate people to go look for information about how to deal with side effects. However, when distress levels are highly elevated or elevated for a long period of time, they will have a disruptive effect on patient's quality of life. For this reason, research in psycho-oncology, including the current study, addresses the psychological well-being of breast cancer patients.

Most studies examining the course of psychological well-being in women with breast cancer regard diagnosis as the major event and assess patients well-being at various, rather arbitrary points in time thereafter. These studies do not take into account that the illness trajectory after a breast cancer diagnosis differs for each patient, depending on the treatment modalities prescribed. As a result, findings regarding the course of well-being are sometimes difficult to interpret and have limited utility for clinical practice (Heim, Valach, & Schaffner, 1997). To illustrate this, when assessing nine months after diagnosis, some women might be in the middle of chemotherapy while others already had their first follow up visit.

For this reason, the design of the current longitudinal study linked assessments to key events rather than merely time since diagnosis (Figure 1.1): (1) the period of suspicion, before diagnosis; (2) the short period right after diagnosis, when treatment has not yet started; (3) the period after surgery, when pathology results and the adjuvant treatment plan have been communicated; (4) the period right after the completion of radiotherapy and/or chemotherapy; (5) the re-entry phase (Stanton et al., 2005), two months after the end of active treatment and (6) the
short-term survivorship phase six months after the end of active treatment. This design enabled us to answer several novel research questions.

First of all, we aimed to identify individual trajectories of change in psychological distress over various clinically meaningful stages after diagnosis (Chapter 2). Most studies that examined the course of psychological outcomes over the first year after diagnosis demonstrated that emotional well-being is most impaired in the first months and gradually improves thereafter (Henselmans, Sanderman, Baas, Smink, & Ranchor, 2009; Hoskins, Budin, & Maislin, 1996; Barez, Blasco, Fernandez-Castro, & Viladrich, 2007; Millar et al., 2005; Stanton et al., 2002). However, this might not hold truth for all patients. For example, Stanton (2005) suggested that the re-entry phase, after the completion of treatment, can again cause elevated levels of distress in some cancer patients and there is some empirical support for this notion (Hinnen et al, 2008; Ward et al, 1992; Ganz, 2004). Ten Kroode (1998) even estimated that two thirds of Dutch cancer patients experience emotional problems in the transition from the period of active treatment to the period of control. Thus, instead of examining overall change at a group level, we tried to look for groups of patients who show similar patterns of psychological distress in the first year after diagnosis. This novel procedure results in more refined knowledge about the course of distress after a breast cancer diagnosis. Moreover, we explored the demographic, medical and personal characteristics that predict these distress trajectories. Among these characteristics was perceived personal control over life.

Second, we examined if and how the various stages in the illness trajectory differentially affected three different types of negative emotions, that is anxiety, depressive symptoms and non-specific psychological distress (Chapter 3). Even though it is well-known that emotional domains overlap to a considerable degree, they do have unique features and unique etiological origins. For example, depressive symptoms are thought to be triggered by loss experiences, while anxiety is thought to be triggered by threat. As different stages in the illness
trajectory each bring specific stressors, these stages might each trigger different types of emotions. We compared women with breast cancer to women without breast cancer to see how the illness stages affect the levels of each of these three indicators.

Lastly, we examined the effect of the length of waiting periods on psychological well-being (Chapter 4). Nowadays, diagnostic speed and surgical waiting lists are used as indicators of the quality of hospital care. Even though it is often assumed that long periods of waiting negatively affect patients' psychological well-being, one could also argue that waiting periods give patients time to adjust and prepare for what is coming. Not many studies have empirically addressed the psychological impact of waiting in mamm care.

1.4 Perceived personal control and psychological adjustment

The second theme of this thesis is the role of perceived personal control in the adjustment process after diagnosis. Since the 80s, researchers from different fields of psychology have theorized about the concept and importance of perceived personal control (Skinner, 1996; Walker, 2001). In the context of disease, three types of personal control can be distinguished, i.e., a sense of control over life in general, over the illness itself and over the consequences of the illness.

First of all, personal control over life in general, also referred to as mastery (Pearlin & Schooler, 1978), reflects the belief that life is not ruled by fate, but that one is personally able to influence the outcomes of important events or situations in life. The concept includes both a view of the self as competent and efficacious and a view of the environment as structured and responsive (Skinner, 1996; Fung, Abeles, & Carstensen, 1999; Weisz & Stipek, 1982). One’s sense of control over life is shaped by cultural beliefs, by personality and by personal experiences (Abeles, 1990). In an attempt to summarize various control-related theories, Peterson and Stunkard (1989) concluded that control is desirable, that it is neither just a disposition nor just an environmental characteristic, that it can be assessed by self-report, and that it constitutes one of the most important ways in which people differ from each other. A strong sense of control over life promotes psychological well-being and protects people against distress under various stressful circumstances (Skinner, 1995; Lefcourt & Davidson-Katz, 1991; Folkman, 1984; Compas, 1987), for example when facing cancer (Penninx et al., 1998; Helgeson, Snyder, & Seltman, 2004; Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989; Ell, Mantell, Hamovitch, & Nishimoto, 1989; Bremer, Moore, Bourbon, Hess, & Bremer, 1997).

Not many studies have taken into account that a sense of control over life not only regulates the impact of stress, but might also be affected by the stressful life event (Pearlin, Lieberman, Menaghan, & Mullan, 1981). Even though a general sense of control is considered to be a rather stable trait, several studies have shown that mastery can decrease due to the confrontation with adverse life events.
(Cairney & Krause, 2008; Vilhjalmsson, 1998). We addressed this two-sided position of mastery in the stress process (Chapter 5) by comparing (1) the level and the course of mastery across three groups facing different degrees of threat, i.e., healthy women (no threat), women diagnosed with breast cancer (threat), and women diagnosed with breast cancer treated with chemotherapy (most threat). In addition, (2) we examined the often assumed but rarely tested stress-buffering effect of mastery. A stress-buffering effect implies that a personal resource gains in importance under stressful circumstances, i.e. the more threat, the stronger the relation between mastery and psychological well-being.

Even though numerous studies showed that a sense of control over life is adaptive when facing cancer, not many studies addressed the question ‘why?’. Recently, MacKinnon and Luecken (2008) promoted the study of mediators to unravel such underlying mechanisms in health psychology research. Mediators are variables that transmit the effect of an independent variable on a dependent variable (MacKinnon, Fairchild, & Fritz, 2007). Knowledge about mediators might not only add to our theoretical understanding of the adaptive value of personal control, but might also have practical significance for the development of interventions for distressed patients. In this study we loosely adopted the stress coping framework of Lazarus and Folkman (Lazarus & Folkman, 1984). Their theory posits that the response to a stressor depends on both the individual’s appraisal of the stressor as well as on the individual’s way of dealing with the stressor. We examined if cancer-specific cognitive appraisal processes as well as two types of active behavior could explain the effect of personal control on the initial response to the breast cancer diagnosis as well as the effect of control on the subsequent psychological adjustment (Chapter 6).

Not only mastery, but also illness specific control perceptions are shown to be related to psychological adjustment to illness. Thompson (Thompson, Nanni, & Levine, 1994) distinguished between perceived control over the disease itself (central control perceptions) and perceived control over the various consequences of the disease, like symptoms, medical care or emotions (consequence-related control perceptions). Consequence-related control is consistently positively related to psychological well-being in diverse patient populations (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Wallhagen & Brod, 1997; Helgeson & Franzen, 1998). Furthermore, in case of uncontrollable diseases like cancer or HIV, consequence-related control is found to be a stronger predictor of adjustment than central control (Thompson et al., 1994; Thompson, Sobolew Shubin, Galbraith, & Schwankovsky, 1993). In fact, several studies have demonstrated that central control over rather uncontrollable illness aspects can have maladaptive effects when such control beliefs are not, or no longer, confirmed (Folkman, 1984; Tomich & Helgeson, 2006; Christensen, Turner, Smith, & Holman, 1991; Helgeson, 1999). A strong belief in personal control over uncontrollable aspects might prevent patients from mentally preparing for a disappointment and might provoke feelings of inadequacy and responsibility. Such findings contrast with
Taylor's cognitive adaptation theory (Taylor, 1983), a well-known framework that suggests that personal control acts as a stress buffer when faced with a setback, even when the sense of control is illusionary to some degree. We examined which of these two lines of reasoning holds true in women with breast cancer who receive disappointing news after surgery (Chapter 7). Moreover, we explored patients' beliefs about how they can exert personal control over cure and we examined the relations between control over cure and various patient characteristics. Based on theory, it was hypothesized that a strong sense of control over cure is related to protective traits reflecting the capacity to adapt to adversity (like optimism) or to characteristics that reflect the need for control (like a high cancer stage or a strong desirability of control in general).

Most chapters of this thesis address the adaptiveness of perceived personal control over life or over the illness. However, successful adjustment to the stressors breast cancer brings, might sometimes require relinquishing personal control, i.e., letting go of certain goals or at least adjusting aspirations temporary. In a famous classical fable (Aesop, 6th century B.C.), a fox spends a whole hot summer's day trying to get a bunch of ripening grapes from a high branch. At last, the fox has to give up and with his nose in the air he walks away and concludes that the grapes must have been sour anyway. In uncontrollable conditions, trying to exert control can be problematic, as such strategies consume scarce resources and can lead to experiences of failure and depression (Rothermund, 2006). In contrast, as the fable shows, the ability to reappraise and to flexibly disengage from unattainable goals might gain in importance under such conditions, as these strategies draw attention and energy away from things in life one can not do or reach any longer. In 1990, a self-report instrument was introduced to assess the individual's general tendency to use assimilative and accommodative coping strategies, named the tenacious goal pursuit (TGP) and flexible goal adjustment (FGA) scales (Brandtstädter & Renner, 1990). We considered it worthwhile to address the validity of the instrument in this study (Mueller & Kim, 2004; Heckhausen, 1997), as it might be of use in future studies explaining adjustment to cancer (Chapter 8).

Before you start reading
Except for Chapter 5, all chapters report on data collected in the FACT study (‘Feelings of control and Adjustment to breast Cancer and Treatment’). Even though parts of this study are described in the various method sections, Box 1.1 presents the FACT facts, i.e., the complete information about the procedure, sample and design. Chapter 5 reports on data collected in the RAAK study (‘Relationship and Adjustment to Cancer’). A description of this study is reported in this chapter's methods section.
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Box 1.1 FACT Facts

FACT procedure
Patient inclusion started in November 2005 and lasted until March 2007. Six hospitals (on seven locations) in the Northern part of the Netherlands were involved in the recruitment of respondents, including one academic and five general hospitals. Women younger than 75 who were referred to the hospital because of a possibly malignant breast tumor were invited to participate in the study in two different ways. The majority of women received an information letter and a short baseline questionnaire at home before the appointment in the hospital (Route 1). When contact by post was impossible due to a too short time period between referral and appointment, nurses informed patients personally during the visit (Route 2). One week after diagnosis, women who returned the consent form (Route 1) or whose contact details were passed on to the researchers (Route 2) were contacted by telephone. Although most women already signed the consent form before diagnosis, for ethical reasons, a confirmation of consent was asked after diagnosis.

When test-results were favorable (i.e., when no lesion was found at all or when the lesion turned out to be benign), women who met the inclusion criteria were included in the reference group. Reasons for exclusions were (1) a serious psychiatric or somatic disorder that implied hospital admission; (2) surgery because of a benign breast disease (e.g., in the case of fibroadenoma); (3) no comprehension of Dutch and (4) a history of cancer. When test-results were not favorable (i.e., when a malignant breast tumor was diagnosed), women who met the inclusion criteria were included in the patient group. Exclusion criteria were (1) a serious psychiatric or somatic disorder that implied hospital admission; (2) no comprehension of Dutch; (3) a history of cancer; (4) treatment with neo-adjuvant chemotherapy; (5) diagnosis of a different type of cancer (e.g., Hodgkin) and (6) an unusual diagnostic protocol (e.g., second opinion). Women who consented, but were not contactable within 6 weeks after the visit, were not included.

FACT design
The six assessments in the patient group were linked to meaningful events (Figure 1.1): shortly before diagnosis (T1); shortly after diagnosis, but before surgery (T2); after surgery, but before the start of adjuvant treatment (T3); right after adjuvant radio- or chemotherapy (T4); in the re-entry phase at 2 months after the end of adjuvant treatment (T5); and in short-term survivorship phase at 6 months after the end of adjuvant treatment (T6). Each patient was matched to a woman in the control group at the time patients were to receive the first questionnaire after the end of treatment (T5). Matching took place to avoid age differences between the patient and the reference group as well as differences in the time passed since diagnosis at the last two assessments. Criteria for matching were (1) an age approximately similar to the patient’s age, (2) diagnosis at the same date as the patient or later (as the match should be able to complete the last two questionnaires at the same time since diagnosis as the patient did) and (3) preferably no missings at earlier assessments. When the match did not return the first questionnaire after matching, a new match was selected if possible. Women in the reference group (both matched and not matched) were asked to complete the first three questionnaires at approximately the same points in time as the patient group, i.e., shortly before diagnosis (T1), right after diagnosis (T2) and 8 weeks after diagnosis (T3). Their design did not include a T4 assessment.
Box 1.1 FACT Facts continued

Only women who were matched to patients received a T5 and T6, at the same time as their matched patient received the last two questionnaires. Since the chapters report on different assessments, the numbering of the assessments is not the same across the various chapters. For this reason, each chapter will start with information on the specific numbering used. Data collection included paper questionnaires at all assessments and two face-to-face interviews in the patient group, one after surgery and one two months after the end of treatment. These face-to-face interviews were administered by trained interviewers and took place at patients’ home. Medical information was collected during the interviews or from patients’ medical files.

FACT sample

A total of 3093 women referred to the hospital because of a suspicion of breast cancer were invited to the study prior to diagnosis. Of these, 1226 gave informed consent (40%), 1094 of which met the inclusion criteria. Of these 1094 women, 912 women could be contacted within 6 weeks after diagnosis, were willing to confirm their pre-diagnosis consent and completed at least one questionnaire after diagnosis (33%). Of these 912 women, 242 women were diagnosed with breast cancer and 670 were not. Of the 242 patients included, 233 women could be matched to a woman of similar age from the control group.

Detailed information about missings and representativeness will be provided for the patient group only. Of the 242 patients, 138 women (57%) missed one or more assessments after diagnosis (not taking into account the pre-diagnosis assessment, which was missed by 38%). These 138 incomplete cases, had missings that were either occasional (41%), due to drop out (10%) or both (6%, first occasional then drop out). The most common reason for drop out among patients was that participation was considered too burdensome. Occasionally missed assessments most often had to do with time constraints. For example, patients included through Route 2 could not fill out a pre-diagnosis questionnaire (T1). Moreover, due to the short time period between diagnosis and first surgery, patients could not always be contacted in time. As a consequence, a small group of patients could not fill out the questionnaire before surgery (T2). Lastly, the questionnaire after surgery (T3) was not always filled out before the start of adjuvant treatment. T3 data provided after the first cycle of chemotherapy were not taken into account (T3 was considered missing), as even the first cycle possibly affected well-being. As a consequence of these missings, the number of respondents differs across the chapters in this thesis, depending on the assessments reported on.

The full patient sample was compared with the regional population of women with breast cancer not older than 75 and treated with surgery (Comprehensive Cancer Center North-Netherlands Cancer Registry, 2005) to examine sample representativeness. The mean age in the patient sample (M = 56, SD = 10, n = 242) was similar to the mean age of all newly diagnosed breast cancer patients in the region (M = 57, SD = 11, n = 1506). The distribution of TNM stages (9% in situ, 40% stage I, 42% stage II, 9% stage III) resembled the distribution in the regional sample as well (11% in situ, 39% stage I, 36% stage II, 12% stage III, 1% stage IV). In the patient sample, 73% was treated with radiotherapy and 43% was treated with chemotherapy, compared to respectively 69% and 39% regionally. In sum, included patients did not differ from the population with respect to age and treatment characteristics.
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