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Psychological well-being and perceived control after a breast cancer diagnosis

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Psychological well-being and perceived control after a breast cancer diagnosis

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Contents

Chapter 1

Introduction

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 characteristics 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%.

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.

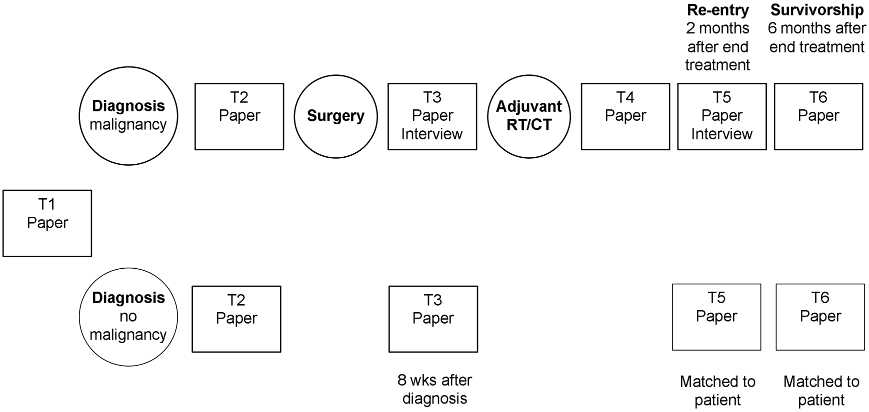
1.3 Psychological well-being in the first year after a breast cancer diagnosis

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

Figure 1.1 *FACT study design*



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 mamma 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. Thomspon (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.

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 fibroadonema); (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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Part 1

Psychological well-being after a breast cancer diagnosis

Chapter 2

Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis

Health Psychology, in press

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Summary

Objective. This paper aims to (1) identify distinct trajectories of psychological distress in the first year after a breast cancer diagnosis in women treated with adjuvant therapy and (2) explore possible predictors of these trajectories, i.e., demographic, medical as well as personal characteristics.

Methods. The 171 patients were assessed after diagnosis, after surgery, after adjuvant treatment, in the re-entry phase and in the (short-term) survivorship phase (2 and 6 months after the end of treatment respectively). Psychological distress was assessed with the GHQ-12.

Results. There were four trajectories of distress: a group that experienced no distress (36%), a group experiencing distress only in the active treatment phase (33%), a group experiencing distress in the re-entry and survivorship phase (15%), and a chronically distressed group (15%). Personality and physical complaints due to adjuvant treatment could distinguish the distress trajectories. Mastery was the only unique predictor.

Conclusions. Most patients were not distressed in response to breast cancer or only temporarily so. Yet, a minority of patients, became or remained distressed after the end of treatment.

Numbering of assessments in this chapter compared to numbering in original design (Figure 1.1):

Chapter 2	T1-T5
Original design	T2-T6

2.1 Introduction

One in eight women in the Western world is diagnosed with breast cancer at some point in life (Ries et al., 2005). Even though prognostic prospects are relatively good, a cancer diagnosis is threatening and confronts women with numerous additional stressors, like treatment and its side effects. Not surprisingly, many studies have addressed the impact of breast cancer on psychological outcomes like distress, anxiety, depression and post-traumatic stress. 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 et al., 2009; Barez et al., 2007; Millar et al., 2005; Stanton et al., 2002; Hoskins et al., 1996). Yet, this might not hold true for all patients.

Most longitudinal studies on adjustment have studied change at the group level. However, it is very likely that patients do not show a single pattern of change over time. Bonanno (2004) suggested that there are four different patterns of adjustment to traumatic life events. He reasoned that, despite common expectations, most people will show resilience and will not report psychological problems at all. Next to a resilient trajectory, he identified a trajectory of recovery after initially high levels of distress as well as a trajectory of stable high levels of distress. Lastly, he recognized that a small group of people will show a delayed response to a stressful life event. Patterns of adjustment after a cancer diagnosis might be similarly and perhaps even more diverse, as not only the cancer diagnosis but also other phases in the illness trajectory can be regarded as stressors. Analysis of adjustment at the group-level, although useful in its own right, might mask such individual differences.

To date, only a few studies have examined the patterns of change in distress among women with breast cancer. Most of these applied case-based analyses (Deshields et al., 2006; Millar et al., 2005; Gallagher et al., 2002). In such analyses, patients are grouped based on whether they score above or below the cut-off of the psychological outcome measure at none, all or several of the assessment points. For example, Deshields et al. (2006) applied the theoretical framework of Bonanno and reported that most women with breast cancer were not depressed at all in the first 6 months after completion of treatment, a small group was depressed at every occasion in this period, two small groups either recovered or became depressed and a last group could not be classified. Gallagher (2002) similarly reported that the majority of women were not distressed either 2 or 6 months after diagnosis, while a considerable number was distressed at both occasions, one group recovered, and a small group became distressed. These results parallel those of Millar and colleagues (2005), who studied the first year after surgery.

Even though these studies provide valuable insight in subgroups showing different patterns of change, and clearly demonstrate that not all women follow the same trajectory, the dichotomizing of scores is a limitation of these case-based analyses. Using a cut-off point may exaggerate small differences between respondents and can create variability that is not representative of the sample (Millar et al., 2005). Thus far, the only study that identified distress trajectories after a breast cancer diagnosis using the full range of scores was conducted by Helgeson and colleagues (2004). They demonstrated that a large group of breast cancer survivors reported high mental functioning four months after diagnosis and retained this level of functioning for the subsequent 4 years. Two other groups showed different degrees of improvement over time, while a fourth gradually deteriorated. Even though the study examined four years of follow-up, most change took place in the first year after diagnosis. The current study focuses on this first year and- unlike the Helgeson et al. study - examines changes in distress over various meaningful illness-related phases.

During the first year, several meaningful events can be identified, including diagnosis, surgery, adjuvant treatment, the transition to survivorship or re-entry phase (Stanton et al., 2005) and finally, the (short-term) survivorship phase. The timing of each of these events differs across patients, depending on, for example, the number of surgeries and the type of adjuvant treatment. Most longitudinal studies, including the trajectory study of Helgeson et al. (2004), do not take these differences into account, and link assessment to time passed since diagnosis or surgery (Henselmans et al., 2009; van de Wiel et al., 2008; Akechi et al., 2006). As a result, findings regarding the course of distress are highly dependent on the chosen points in time, often difficult to interpret, and have limited utility for clinical practice (Heim et al., 1997). For this reason, the design of the current study links assessments to key events in the first year rather than merely time since diagnosis: (1) the short period right after diagnosis, when treatment has not yet started, (2) the period after surgery, when pathology results and the adjuvant treatment plan have been communicated, (3) the period immediately following the completion of radiotherapy and/or chemotherapy, (4) the re-entry phase two months after the end of active treatment and (5) the short-term survivorship phase six months after the end of active treatment. As only patients treated with radiotherapy and/or chemotherapy went through all of these five phases, we exclusively focused on this group - the clear majority of patients.

After having identified the trajectories of adjustment, the second aim of the current study was to explore demographic, medical and personal characteristics that might predict these trajectories. First, we were interested in the predictive effect of *age*. It has been suggested that cancer is more disruptive in the lives of younger women (Costanzo et al., 2007; Mosher & Danoff-Burg, 2005; Schroevers et al., 2004), as they are dealing with work aspirations, child care, and plans for the future and are not normatively prepared for health problems. We also included *educational level* as a possible predictor, as research suggests a relation between low educational level and poor adjustment to cancer (e.g., Knight et al., 2007). Second, we explored whether several *medical characteristics* could predict trajectories in distress, i.e., cancer stage, surgery type, the combination of radiotherapy and/or chemotherapy and hormone therapy. Even though it is sometimes concluded that medical characteristics are largely unrelated to psychological well-being among people with cancer (Bardwell et al., 2006), there are studies that do show relations with distress (Henselmans et al., 2009; van't Spijker et al., 1997; Hoskins et al., 1996). Besides objective treatment characteristics, we examined the role of *physical complaints* due to surgery and due to radio-, chemo- and/or hormone therapy (RT/CT/HT).

In addition to demographic and medical characteristics, we examined the effect of perceived personal control, a personal characteristic that has received considerable attention in studies on adjustment to illness. Personal control over life or *mastery* constitutes the belief that life is not ruled by fate, but that one is personally able to influence the outcomes of important events or situations (Pearlin & Schooler, 1978). Several studies have demonstrated the adaptive effect of mastery in people facing cancer (Henselmans et al., 2009; Helgeson et al., 2004; Penninx et al., 1998; Bremer et al., 1997; Ell et al., 1989a; Ell et al., 1989b). Lastly, we examined the predictive effect of *optimism* (i.e., the general expectancy that good instead of bad things will happen) and *neuroticism* (i.e. the tendency to experience negative emotions). Previous research has shown that optimism promotes psychological well-being in the face of cancer (Carver et al., 1993), while neuroticism is related to maladjustment (Hinnen et al., 2008; Ranchor et al., 2002).

In sum, this paper aims to (1) identify subgroups of women with distinct patterns of psychological distress over various stages in the illness trajectory in the first year after diagnosis and (2) to explore several possible predictors of these patterns (i.e., demographic, medical and personal characteristics).

2.2 Method

Procedure

Six hospitals in the Northern part of the Netherlands were involved in the recruitment of respondents. The study protocol was approved by the Medical Ethical Committees of all hospitals. Women who were referred to the hospital because of a suspicion of breast cancer were invited to participate by mail. Women were eligible if they (1) were 75 years old or younger, (2) did not have a serious psychiatric disorder or a somatic disorder that implied hospital admission, (3) comprehended Dutch, (4) followed the usual diagnostic protocol and (5) did not have a history of cancer. Lastly, patients treated with neo-adjuvant chemotherapy before surgery were excluded, as we wanted to avoid differences in the order of these treatment modalities. Women were not paid for their participation.

Design

Assessment took place at meaningful events: shortly after diagnosis but before surgery (T1; on average 12 days post-diagnosis, SD = 7); after surgery but before the start of adjuvant treatment (T2; on average 51 days post-diagnosis, SD = 18); right after adjuvant treatment with RT/CT (T3; on average 170 days post-diagnosis, SD = 62); in the re-entry phase at 2 months after the end of adjuvant treatment with RT/CT (T4; on average 220 days post-diagnosis, SD = 62); and in the short-term survivorship phase 4 months later (T5; on average 350 days post-diagnosis, SD = 70). Thus, on average, all phases took place within one year of diagnosis. Some women were treated with hormone therapy (48%; usually 5 years) or trastuzumab (Herceptin; 15%; usually 1 year), starting after the end of RT and/or CT. Because of their considerable duration, these treatment modalities were not taken into account in the design of the study. That is, the end of radio- and/or chemotherapy was considered the end of the active treatment phase. Surveys were administered at all time points and two face-to-face interviews were conducted, one after surgery and one two months after the end of active treatment.

Sample

A total of 3093 women were invited to the study prior to diagnosis. Of these, 1226 gave informed consent prior to diagnosis, 1094 of whom met the inclusion criteria. Of these 1094 women, 912 women were contacted within 6 weeks after diagnosis and were willing to confirm their pre-diagnosis consent. Of these 912 women, 242 women were diagnosed with breast cancer of whom 203 were treated with adjuvant radio- or chemotherapy.

Of these 203 women, 105 women missed one or more of the 5 distress assessments. These missed assessments were either occasional (*n* = 70), due to drop out (*n* = 22) or both (*n* = 12, first occasional than drop out). The most common reason for drop out was that participation was considered too burdensome. Occasional missed assessments most often had to do with time constraints between diagnosis and first surgery (T1) and between last surgery and the start of adjuvant chemotherapy (T2) due to rapid scheduling of treatment. T2 data provided after the first cycle of chemotherapy were counted as missing, as even the first cycle possibly affected distress levels.

Even though the procedure that we used (TRAJ finite mixture modeling) can handle missing values (Nagin, 2005, page 36), we chose to exclude 32 women who missed more than 2 of the 5 distress assessments as well as women who did not have at least one early assessment shortly after diagnosis (T1 or T2) and one late assessment in the re-entry phase (T4 or T5). Assigning women who did not meet these criteria to a distress trajectory group would imply too much uncertainty. The final sample consisted of 171 women, of whom 73% had a distress score at T1, 90% at T2, 95% at T3, 100% at T4 and 95% at T5. These 171 women did not differ from the excluded 32 with respect to age, medical characteristics and most distress assessments. However, 6 of the 32 women who did complete the T4 questionnaire, yet missed out on others, were more distressed at that time than the 171 included women. The 171 women in the current sample were largely similar to the regional population of women younger than 75 who were diagnosed with breast cancer and treated with adjuvant radio- or chemotherapy with respect to age and cancer stage (Comprehensive Cancer Center North-Netherlands Cancer Registry, 2005).

Instruments

Psychological distress was assessed with the 12-item version of the General Health Questionnaire (Goldberg & Williams, 1988). The GHQ-12 is a well-validated instrument (Goldberg et al., 1997), which is often used in medical populations, including women with breast cancer (Nosarti et al., 2002; Parle et al., 2001). Respondents were asked, for example, if lately they were able to concentrate on what they were doing, lost sleep over worries, felt they played a useful part in things, felt capable of making decisions or felt constantly under strain. Respondents were instructed to compare their present state with their usual state. The total scale score was calculated by counting the number of items for which respondents indicated a state that was 'worse' or 'much worse' than usual. Scores ranged from 0-12. Alpha's ranged from .84 (T1) to .90 (T4 and T5). In patient samples, a score lower than 2 indicates no distress, scores between 2 and 3 indicate a 'borderline' case and scores of 4 or higher indicate psychological morbidity (Parle et al., 2001; Goldberg & Williams, 1988). In the general Dutch female population, 74% report no distress at all (Verhaak et al., 2005); estimates of psychological morbidity range from 10% to 19% (Koeter & Ormel, 1991).

Medical and treatment characteristics (surgery type, type of adjuvant treatment) were retrieved from patients' medical files and from patients own reports.

Common *complaints after surgery* (0-8) were assessed at T2 (e.g., pain in the affected breast, pain in arm/shoulder, difficulties moving, etc.). Common complaints due to RT (0-9) and CT (0-10) were assessed at T3, right after the completion of these two types of treatment. Common complaints due to HT (0-10) were assessed at T4, when this modality had started for some but not for all patients. The *complaints due to RT/CT/HT* were summed (0-29).

Mastery was assessed after surgery (T2) and two months after the end of treatment (T4) with the 7-item Mastery Scale (Pearlin & Schooler, 1978). A sample item is: 'What happens to me in the future mostly depends on me'. The five response categories ranged from (1) 'fully agree' to (5) 'fully disagree.' Alpha was .79 at T2. *Optimism* was assessed after surgery (T2) with the 6-item Life Orientation Test-Revised (Scheier et al., 1994). A sample item is 'In uncertain times, I usually expect the best'. The five response categories ranged from 'fully agree' to 'fully disagree'. Alpha was .75. *Neuroticism* was assessed after surgery (T2) with a 12-item subscale of the NEO-Five Factor Inventory (Hoekstra et al., 2003; Costa, Jr. & McCrae, 1992). A sample item is: 'I often feel tense and jittery'. The five response categories ranged from 'fully agree' to 'fully disagree'. Alpha was .84.

Overview of the analysis

Identifying trajectories

To get a sense of the distinct patterns of psychological distress present in the data, we started with a visual exploration[1] of the individual distress trajectories. To get a more objective picture, we subsequently applied a SAS finite mixture model procedure called TRAJ (Jones et al., 2001). This technique can model variables with a censored normal distribution, like the distress measure in the current paper with a cluster of data at the scale's minimum. Even though it is possible to model flat, linear, quadratic and even cubic patterns, the technique is most appropriate for data with values changing smoothly as a function of the independent variable (e.g., time, age). The distress patterns in our data showed sharp changes. To be able to capture these patterns, we included the five occasions as time varying covariates in the model, as suggested by Jones (Jones, 2005). This means the resulting trajectories are a function of an intercept representing the level of distress at T1 and four estimates representing the effects of T2, T3, T4, and T5 on the level of distress compared to the level at T1. We tested models that ranged from 1 to 5 trajectory groups. As there is no gold standard for defining the correct number of trajectories, we made use of several criteria simultaneously. First, we inspected the Bayesian Information Criterion (BIC) and the Akaike Information Criterion (AIC). These criteria take into account the improvement in model fit when one adds more parameters (e.g., groups), but also reward parsimony by extracting a penalty for additional parameters. The higher BIC or AIC, the better the model fits[2]. Research has shown that both criteria perform well, but that the BIC is the more conservative criterion of the two, biased toward models with fewer groups (Brame et al., 2006). If the BIC and AIC did not unanimously point to the best fitting model, we based model selection on the conceptual meaningfulness of the addition of a group. That is, an additional group would need to show a pattern clearly different from the patterns of the groups in the model with fewer groups, should match with one of the patterns identified through visual exploration of the data, and should contain a substantive number of participants (at least 5%). To judge the adequacy of the final model we examined if the posterior probabilities (i.e., a participant's probability of belonging to a certain trajectory group) averaged to at least .70 for each trajectory group (Nagin, 2005, page 88). Furthermore, to test whether missing data affected model selection, we examined trajectory group differences in data completeness. Moreover, we reran the analysis on the 98 women with complete data.

Distinguishing trajectories

To take into account the uncertainty of group assignment when examining possible predictors, we used the posterior group membership probabilities as weights. That is, the data of women who were assigned to a group with high certainty were given more weight than the data of women who were assigned to a group with less certainty (same procedure as Stiffman et al., 2007). First, the relation between group membership and the categorical characteristics were explored with chi-square tests. Moreover, we explored the relation between group membership and the possible continuous predictors in analyses of variance (ANOVA). Estimates of effect size (Cohen, 1992) will be presented (small, d = 0.2; medium, d = 0.5; large, d = 0.8). Characteristics that were significantly related to group membership were entered simultaneously in a multinomial logistic regression analysis, again using the posterior probabilities as weights. Due to case weighing and missing values on the predictors, sample sizes are small and results need to be interpreted with caution.

2.3 Results

Descriptives

Table 2.3 (first column) presents information on the educational level and several medical characteristics of the total sample. Table 2.4 (first column) shows the mean age, the mean number of physical complaints and the mean levels of mastery, optimism and neuroticism. The mean levels of distress at a group level were stable until the end of treatment and started to decrease in the re-entry phase, *M*(*SD*) at T1 = 3.3 (3.2), T2 = 3.6 (3.5), T3 = 3.5 (3.5), T4 = 2.6 (3.4), T5 = 2.2 (3.5).

Model selection

Table 2.1 shows the BIC, AIC and the estimated group probabilities of the tested models. The BIC criterion suggested that the three-group model fitted best, whereas the AIC criterion favored the four-group model. Thus, we turned to our non-statistical model selection criteria. We chose to maintain the four group model for three reasons (Table 2.2; Figure 2.1). First, the additional trajectory group that appeared in the four group model was clearly different from the patterns represented by the three-group model. The additional trajectory group reflected increasing distress over time. Second, this group was also detected during our visual exploration of the data. Finally, the smallest group in the four-group model still contained a substantive number of participants (15%).

The average posterior probabilities were higher than .70 for each trajectory group (.90, .79, .81 and .91 respectively), which supported model adequacy. Furthermore, the 4 groups did not differ with respect to the number of completed questionnaires in total nor per occasion. To test whether missing data affected model selection, we ran the same analysis on the 98 women with complete data. With this smaller sample, again the BIC preferred the three-group model and the AIC the four-group model. The estimated group membership probabilities of the four-group model (44%, 30% ,13%, 13%) largely resembled those found in the full sample (36%, 33%, 17%, 15%). Although not all parameters (i.e., trajectory shapes) were equal[3], the trajectories in the smaller sample of women with

Table 2.1 *Model selection results*

			Estimated probabilities (estimated % in each group)				
No. of groups	BIC	AIC	1	2	3	4	5
1	-1721.43	-1712.00	100%				
2	-1626.00	-1607.15	68%	32%			
3	-1607.42	-1579.14	39%	44%	17%		
4	-1614.94	-1577.24	36%	33%	17%	15%	
5	-1626.33	-1579.20	7%	36%	37%	15%	5%

complete data reflected the same four patterns as those found in the full sample. In sum, model selection was largely unaffected by missing data.

Description of distress trajectories

Women in *Group 1* (36%[4]) did not experience any distress after diagnosis (Figure 1). The predicted as well as observed group average right after diagnosis (T1) was well below the cut-off for morbidity (>= 4) and decreased after surgery (T2) to a stable zero level. Women in *Group 2* (33%) started out with a rather high level of distress indicative of psychological morbidity (>= 4) and remained distressed until the end of treatment (T3). They recovered two months after the end of treatment (T4) to a level indicating no distress (< 2). By six months after the end of treatment (T5) they were rather similar to Group 1. Women in *Group 3* (15%) started out mildly distressed, but reported an increase in distress at T3 reaching a maximum level of distress at T4 ($M = 5.7$). There was some recovery by the last assessment. Women in *Group 4* (15%) started out with very high distress and remained high in distress along the illness trajectory. For simplicity, for the remainder of this paper we will refer to Groups 1 through 4 as the *no-distress* group, the *recovery* group, the *late distress* group and the *chronic distress* group.

Distinguishing distress trajectories

Table 2.3 presents the distribution of the categorical characteristics in each trajectory group, as well as the chi-square test results. Table 2.4 presents the means on the continuous characteristics in each trajectory group, as well as the ANOVA test results. Posterior probabilities were used as weights. Only significant predictors of group membership were included in the final multivariate analysis.

Age differences and differences in educational level were not significant. Cancer stage, objective treatment characteristics and physical complaints due to surgery did not differ significantly across the four groups either. Groups did differ significantly on the number of complaints due to RT, CT and/or HT. The no-distress trajectory group reported less complaints than the other three groups ($p <$

.05; medium sized effects), which reported a similar number of complaints.

In contrast to the demographic and objective medical characteristics, the personal characteristics did have a significant effect on group membership. Compared to the no-distress trajectory group, women in the recovery group (*p* < .01; medium to large effect sizes) and particularly those in the chronic group (*p* < .001; large effect sizes) had a lower sense of mastery, were less optimistic and had higher scores on neuroticism. The no-distress and the late group were similar with respect to these characteristics. Only high scores on neuroticism could distinguish women who recovered from women who remained distressed (*p* = .03; medium sized effect).

The three personal characteristics as well as complaints due to RT/CT/HT were entered simultaneously in a multinomial logistic regression analysis. Posterior

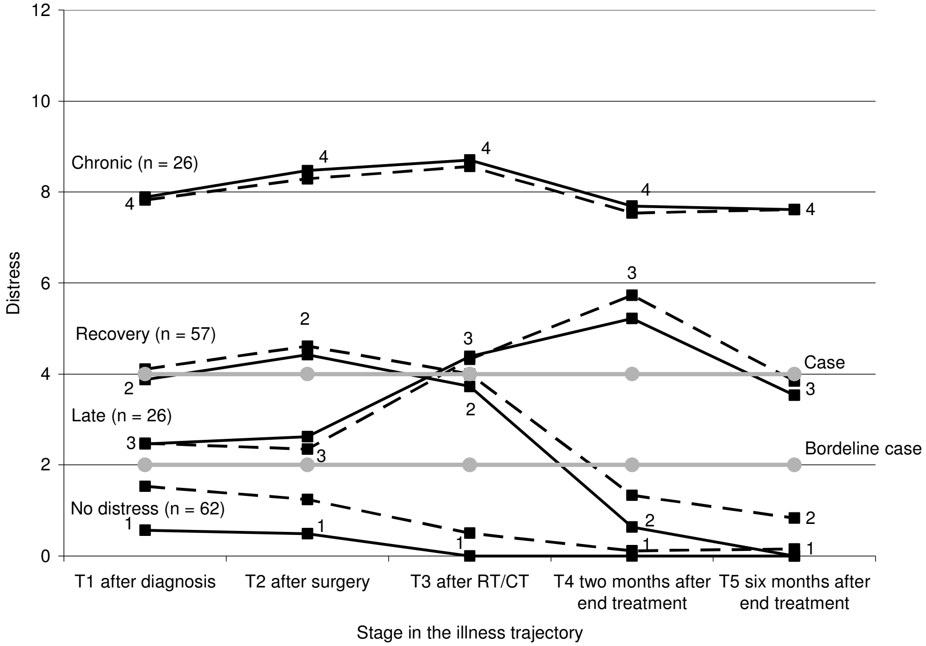
Table 2.2 *Four-group model parameter estimates*

		Coefficient [a]	*SE*	Sig.
Group 1 (no-distress)	Intercept (T1)	0.57	0.55	0.30
	T2	- 0.08	0.68	0.91
	T3	- 1.78	0.89	0.05
	T4	- 3.82	0.90	<.005
	T5	- 4.05	0.93	<.005
Group 2 (recovery)	Intercept (T1)	3.87	0.73	<.005
	T2	0.55	0.76	0.47
	T3	- 0.14	0.79	0.86
	T4	- 3.24	0.91	<.005
	T5	- 4.45	0.97	<.005
Group 3 (late)	Intercept (T1)	2.47	0.96	0.01
	T2	0.16	1.03	0.88
	T3	1.92	1.13	0.09
	T4	2.76	1.52	0.07
	T5	1.07	1.37	0.44
Group 4 (chronic)	Intercept (T1)	7.89	0.83	<.005
	T2	0.58	0.98	0.55
	T3	0.82	0.99	0.41
	T4	- 0.20	1.04	0.85
	T5	- 0.28	1.03	0.79

[a] The intercept represents the level of distress at T1. The estimates T2-T5 represent the level of distress at these occasions relative to the level at T1. Thus, the significance levels indicate if the levels of distress at T2-T5 differ significantly from the level at T1. When the estimates T2-T5 indicate that the predicted levels of distress decreased below zero (in Group 1 and 2), this means more than 50% of the group had a distress score of 0 at that occasion. Figure 2.1 shows these levels at zero (as possible distress scores range from 0 to 12).

probabilities were used as weights. The pseudo R-square was 35% (Nagelkerke). Only mastery (X^2= 12.26, $p < .01$) was still a significant predictor of group membership. Women with a strong sense of mastery were more likely to belong to the no-distress group than to the recovery (odds ratio = 0.82, $p < .01$) or the chronically distressed group (odds ratio = 0.77, $p < .01$).

Figure 2.1 *Predicted and observed levels of distress for each trajectory group at each stage in the illness trajector*



Predicted is solid; Observed is dashed. Scores between 2-3 indicate a 'borderline' case, scores of 4 or higher indicate possible psychological morbidity (case). Note 1: as the design of this longitudinal study was based on different meaningful stages in the illness trajectory, the stages in the figure are equally spaced. However, the first two assessments were very close to each other, while the latter three were further apart. Note 2: Due to the censored nature of the data, there was a relatively large difference between the observed and predicted means in group 1 at the first two occasions, as the predicted mean takes into account censoring at zero.

2.4 Discussion

Four distinct trajectories in psychological distress were identified in women with breast cancer who were treated adjuvantly. First, there appeared to be a large group of women who experienced no distress at all (36%). This finding is in line with the results of trajectory analyses by others (Deshields et al., 2006; Helgeson et al., 2004; Gallagher et al., 2002) and seems to support the growing body of evidence that not all people experience psychological problems after a cancer diagnosis (Hinnen et al., 2008; Coyne et al., 2004; van't Spijker et al., 1997).

Table 2.3 *Categorical demographic, medical and treatment characteristics of the total sample and each trajectory group and chi-square test results*

Predictor	Total sample %	Trajectory groups weighted %				Chi-square results	
		No-distress	Recovery	Late	Chronic	Chi-square	Sig.
Educational level							
Elementary/low-level professional	41%	51%	36%	41%	25%	6.99	0.32
Intermediate-level professional	36%	31%	43%	27%	46%		
High-level professional/ academic	23%	18%	21%	32%	29%		
Cancer stage							
0/1	41%	37%	48%	33%	43%	1.81	0.61
2/3	59%	63%	52%	67%	57%		
Mastectomy	20%	13%	27%	19%	35%	5.28	0.15
Adjuvant therapy RT / CT							
Radiotherapy only	46%	51%	49%	43%	38%	6.51	0.37
Chemotherapy only	14%	6%	16%	14%	25%		
Radio- and chemotherapy	40%	44%	36%	43%	38%		
Hormone therapy	48%	42%	48%	57%	52%	1.70	0.64

Weighted sample sizes differ due to missing values on the predictors, i.e. no-distress 53 - 56, recovery 44 - 46, late 21 - 22 and chronic 23 - 24.

Second, a similarly large group showed a pattern of *recovery,* experiencing distress only right after diagnosis and in the active treatment phase (33%). This trajectory matches the pattern most often reported in studies examining the course of distress at the group level (Henselmans et al., 2009; Barez et al., 2007; Millar

Table 2.4 *Group means, standard deviations and ANOVA test results for continuous characteristics*

Predictor (possible range)	Total sample M (SD)	Trajectory groups weighted M (SD)				ANOVA results	
		No-distress	Recovery	Late	Chronic	F (df)	Sig.
Age (<= 75)	54.8 (9.0)	56.6 (8.9)	53.8 (9.6)	55.6 (8.5)	51.5 (8.2)	2.05 (3,142)	.11
Complaints after surgery	2.4 (1.6)	2.1 (1.7)	2.3 (1.4)	2.6 (1.7)	3.0 (1.7)	1.97 (3,140)	.12
Complaints RT, CT, HT	7.3 (4.9)	5.8 (4.4)	8.0 (4.6)	8.5 (4.8)	8.7 (5.7)	3.02 (3,132)	.03
Mastery T2 (7 - 35)	25.5 (4.3)	27.7 (4.5)	24.3 (3.3)	25.9 (2.8)	22.5 (4.0)	12.20 (3,142)	.00
Optimism (6 - 30)	23.4 (3.1)	24.7 (2.8)	22.7 (2.8)	23.8 (3.2)	22.0 (3.2)	6.54 (3,141)	.00
Neuroticism (12 - 60)	28.1 (6.2)	25.4 (5.6)	29.3 (5.5)	27.1 (6.8)	32.6 (6.2)	9.58 (3,142)	.00

RT Radiotherapy, CT chemotherapy, HT hormone therapy; Sample sizes differ due to missing values on the predictors, i.e., no-distress 52 - 56, recovery 39 - 45, late 19 - 21 and chronic 22 - 24.

et al., 2005; Stanton et al., 2002; Hoskins et al., 1996). Because of the unique design of our study we were able to show that this recovery takes place during the re-entry phase, once active treatment in the hospital is over. Third, a small but substantial number of patients were classified in a group showing a *late* increase in distress in the re-entry phase (15%). This increase in distress seems to support qualitative and anecdotal reports (Stanton et al., 2005; ten Kroode & H.F.J., 1998) and scarce empirical evidence showing that there are problems associated with the transition from being a cancer patient to being a cancer survivor (Hinnen et al., 2008; Ward et al., 1992), although not all studies have confirmed this late increase in problems (Costanzo et al., 2007). A clinically interesting observation is that, contrary to the no-distress group, women in the late trajectory group already reported mildly elevated distress levels shortly after diagnosis. This finding suggests that women who are not distressed shortly after diagnosis are not likely to develop problems in later stages. Yet, future research should replicate this finding. Finally, a small but substantial group experienced *chronically* elevated levels of distress (15%).

In terms of distinguishing among the trajectories, results showed that groups differed in the number of complaints due to adjuvant treatment as well as in mastery, neuroticism and optimism. Compared to the other three groups, women who showed a no-distress trajectory after diagnosis reported the least physical complaints due to adjuvant treatment and had the strongest personal resources (high optimism and mastery, low neuroticism). Mastery was the only characteristic that uniquely predicted group membership in a multivariate analysis. In an earlier study (Henselmans et al., in press), we demonstrated that the protective effect of mastery on psychological distress can be explained by differences in threat appraisal and in coping self-efficacy. That is, women with a strong sense of control over life worried less about the impact cancer had on their life and had more confidence in their personal coping skills than women with a weak sense of control.

Two specific group contrasts might have particular practical significance. That is, can we distinguish (1) women who report no distress from women who will report distress in later stages and (2) women who recover from women who do not? With respect to the first contrast, women reporting late distress could only be distinguished from the no-distress group by a higher number of complaints due to adjuvant treatment. Besides physical complaints, there might however be several other reasons for the emergence of psychological problems in the reentry phase. Distress in the reentry phase might be a delayed psychological response to the hectic period of diagnosis and treatment. Once in a calmer period, the cancer experience might finally start to sink in for some patients, causing a delayed increase in distress. Late distress might also be a consequence of specific cancer-related stressors that emerge in the reentry phase. Costanzo and colleagues (2007) reported that - besides side effects and physical problems - frequently mentioned sources of stress in the reentry phase are fears of recurrence and problems with getting back to life as usual. Future research might examine these potential predictors of 'late' distress in more detail, as cancer-related distress in this phase might be preventable, perhaps more so than distress in the early period after diagnosis. With respect to the second contrast, women with chronic high scores on distress had higher scores on neuroticism than women who recover. Neuroticism is an often reported risk factor for psychological distress under 'usual' as well as under stressful circumstances (Hinnen et al., 2007; Ranchor et al., 2002). It remains unclear if the chronic high levels of distress were due to difficulties in adjusting to cancer or due to previous psychological problems, either triggered by or entirely unrelated to cancer. Future research should examine the possible predictors of stable high distress in more detail.

The current study has several limitations. First of all, because our design included early assessments after diagnosis and assessments that were linked to events like surgery and the start of adjuvant treatment, we had a non-neglible amount of missing data. However, the trajectory identification appeared to be largely unaffected by these missing data, i.e., groups did not differ in data completeness and the same trajectory model was found in the subset of women with complete data. Moreover, representativeness seems unaffected, as the 171 patients appeared to be comparable to the total regional population of women with breast cancer younger than 75 years who were treated adjuvantly with respect to cancer stage and age (Comprehensive Cancer Center North-Netherlands Cancer Registry, 2005). The data do, however, suggest that participants who had to be excluded from the analyses because of incomplete data might have been more distressed than participants who were included. Second, the sample sizes of the four trajectory groups were small (the smallest had 26 women). This decreased the power to detect relevant predictors. For this reason, the results of the predictive analyses in this paper should be regarded as exploratory; future research should examine the same predictors in a larger sample. Furthermore, although we examined several demographic, medical and personal characteristics, there might have been other variables that could have distinguished the distress trajectories, such as social support or the presence of previous psychological problems. In addition, we lacked systematic information on recurrence or disease progression during the 6 months after the end of treatment. However, recurrence in the first year after surgery is rare (3%; Kimura et al., 2007). Lastly, we would like to suggest several additional directions for future research. Future studies should examine how distress trajectories in the first year are related to distress in the survivorship phase. Moreover, as the current study identified trajectories in general distress only, future research should detect trajectories in cancer-specific distress, like fear of recurrence or other cancer-specific worries.

The current study applied two relatively novel methods to study the course of distress after a cancer diagnosis. First, the design of the study was linked to clinical and therefore psychological meaningful events in the illness trajectory, making both the interpretation of results and translation to practice much easier and so the more relevant. Second, instead of examining change at the group level, we looked at individual differences in patterns of adjustment. These individual patterns were aggregated at group level, resulting in four groups with a similar course of distress within the various groups and four very distinct patterns of distress over time. This novel procedure resulted in more refined knowledge about the course of distress after a breast cancer diagnosis. While the majority of women was not distressed in response to breast cancer - or only during active treatment, a minority became or remained distressed in the re-entry and survivorship phase. Findings of studies might eventually direct the design and timing of tailored psychosocial interventions if more researchers would adopt this approach.

Footnotes

[1] A program written in R that enables visual classification of individual trajectory graphs in a user-friendly manner is available at http://www.stat.cmu.edu/~hseltman/RVisClust/

[2] The majority of programs other than Proc TRAJ define AIC and BIC as -2 times the AIC and BIC values used in Proc TRAJ. For these programs, a lower value indicates better fit.

[3] The shapes of the four trajectories were largely the same in the sub-sample of women with complete data. There were three minor differences. In women with complete data, Group 4 showed a small increase in distress from T4 to T5. Furthermore, Group 2 did not decrease to a zero level. Lastly, Group 3 showed a more exaggerated pattern, i.e. the peak at T4 was higher and the level at T5 was lower. However, these differences did not affect the interpretation of the trajectories as no-distress, recovery, late and chronic.

[4] This is the 'assigned' probability, based on the assignment of participants to groups according to the highest posterior probability assignment rule. The group's estimated probability (Table 2.3) is based on the estimated parameters in the model. The reasonable close correspondence between the two supports model adequacy (Nagin, 2005; page 89).

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Chapter 3

Distinct trajectories of anxiety, depression and nonspecific distress following diagnosis of breast cancer

Submitted

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Summary

Objective. To determine whether distinct trajectories of three indicators of negative affect, i.e., anxiety, depressive symptoms and nonspecific distress can be identified in the first year after a breast cancer diagnosis.

Methods. The STAI-6, the CES-D, and the GHQ-12 were completed five times by 201 women diagnosed with breast cancer who were treated with radio- and chemotherapy, and by an age-matched control group of 194 women who did not have cancer. Assessments in patients took place shortly after diagnosis (T1), after surgery (T2), at the end of adjuvant treatment (T3), and in the re-entry (T4) and short-term survivorship phase (T5). Matched controls were assessed at the same points in time.

Results. The immediate emotional response after diagnosis was characterized by anxiety, while later phases were characterized by nonspecific psychological distress. Depressive symptoms were hardly elevated. Half a year after the end of treatment, women with breast cancer were no more anxious, depressed, or distressed than matched control women.

Conclusions. Even though the three emotions are highly inter-correlated, distinct trajectories in anxiety, depression and distress were identified. Implications for psychosocial screening and psycho-social interventions in breast cancer treatment settings were discussed.

Numbering of assessments in this chapter compared to numbering in original design (Figure 1.1)

Chapter 3	T1-T5
Original design	T2-T6

3.1 Introduction

The diagnosis of breast cancer is not a single adverse life event, but the start of a stressful period with different phases, each with different types of stressors triggering various emotional responses. The most frequently reported indicators of negative affectivity are *anxiety*, *depressive symptoms* and *nonspecific psychological distress* (van't Spijker et al., 1997). In general, the findings show that such negative emotions are elevated in the first months after diagnosis and gradually get back to lower levels thereafter (Hinnen et al., 2008; Millar et al., 2005; Alferi et al., 2001; Osowiecki & Compas, 1999; Den Oudsten et al., 2009). However, not many studies included these three indicators to examine how they are *differentially* affected by the various stages in the illness trajectory in the first year.

Different negative emotions

Anxiety is triggered by threat or imminent danger (Finlay-Jones & Brown, 1981). It is the sensation of fear characterized by physical symptoms such as palpitations and sweating, behavioral symptoms like restlessness and reassurance seeking, and cognitive symptoms like worry and poor concentration (Stark & House, 2000). While anxiety is distinguished by hyperarousal, *depression* is a state mainly characterized by a low mood and a lack of interest or pleasure in normally enjoyable activities. Such gloominess is the consequence of an experienced irrevocable loss (Finlay-Jones & Brown, 1981) and is associated with a sense of hopelessness or helplessness (Seligman, 1972; Seligman, 1975; Brothers & Andersen, 2009). Lastly, *nonspecific psychological distress*, although an often used indicator of negative affectivity, is a theoretically less well defined global construct which has been operationalised in various ways (Hinnen et al., 2008; Bleiker et al., 2000; Parle et al., 2001). The term is often used to refer to the constellation of symptoms that are common in many emotional disorders, but are not specific to any single disorder (Dohrenwend et al., 1980). In the cancer-context distress had been defined as a 'multi-factor unpleasant emotional experience' (Holland, 1999). Some measures of nonspecific psychological distress specifically focus on self-reported discontinuity in normal functioning (Goldberg & Williams, 1988). As nonspecific distress includes various types of negative emotions, it might be triggered by both threat and loss experiences, as well as by other types of adversity.

Even though it is well known that these different types of negative affectivity share common components and are often experienced simultaneously (Watson, 2009), they also reflect unique symptoms which are thought to be triggered by different types of events. For this reason, the three indicators might be differentially affected by the various stages in the first year after a breast cancer diagnosis. For example, the review of Stiegelis et al. (2004) showed that before the start of radiotherapy, anxiety was more salient than depression, while during and after radiotherapy, anxiety decreased and depressive symptoms increased.

The differential course of anxiety, depressive symptoms and nonspecific distress over various phases in the first year after diagnosis has not been investigated in previous studies.

Different illness phases

The illness trajectory starts with a definitive diagnosis after an uncertain period of waiting. Soon after diagnosis, most women undergo one or more surgeries to remove the malignancy. In these early phases after diagnosis, when patients have just learned they have a life-threatening disease that might involve important life changes, anxiety might be the most salient negative emotion. After surgery, a majority is treated with adjuvant radio- and/or chemotherapy, which takes about 1 to 6 months. When adjuvant treatment is completed, women move to a re-entry phase (Stanton et al., 2005), which constitutes the transition to the (short-term) survivorship phase. In these later phases, depressive symptoms might become more prominent (Nosarti et al., 2002), as patients start to realize the implications of the disease and might need to process various types of loss, for example a loss of physical integrity (Barraclough, 1994). These later stages might however also trigger anxiety, due to for example the risk of a recurrence (Thomas et al., 1997; Lampic et al., 1994). With respect to the broadly defined nonspecific distress, it is hard to formulate any specific expectations.

Each of the phases after diagnosis is characterized by specific stressors and the timing of each of the phases differs across patients, depending on, for example, the number of surgeries and the type of adjuvant treatment. Often, longitudinal study designs do not take differences between various phases into account and assess emotions at rather arbitrary points in time (Henselmans et al., 2009; van de Wiel et al., 2008; Akechi et al., 2006). Heim et al. (1997) however demonstrated that emotional well-being depended more on illness phase than on time since diagnosis. Results based on a study design linked to illness phases might have greater utility for clinical practice than time-based designs, e.g., they might show medical specialists what type of emotions to expect when they meet with patients in the different phases after diagnosis. For this reason, the current study examined the course of negative emotions over various illness *phases* in the first year after diagnosis. To allow for conclusions regarding the extent to which negative emotions among women with breast cancer can be attributed to their cancer, a reference group was included. Women who visited the hospital because of a suspicion of breast cancer, but subsequently were found to have no tumor or a benign tumor, participated at similar points in time after diagnosis.

Knowledge on distinct trajectories in anxiety, depression and nonspecific distress might have important implications for the timing of psychosocial interventions and for screening. Psychologists interested in tailoring and evaluating psychosocial interventions might benefit from knowledge on the natural course of distinct emotions. For example, such knowledge might suggest what types of interventions should be available in different phases of the illness trajectory.

Furthermore, such knowledge might guide the practice of screening, i.e., the choice of the screening instrument as well as the timing of screening. More and more attention is paid to methods of detecting cancer patients with psychological problems, irrespective of their nature, in an early stage (for an overview of screening instruments, see Carlson & Bultz, 2003; or Mitchell, 2007). Often, an instrument that assesses just one domain of negative affectivity is chosen and is administered at an arbitrary point in time. When the overlap between various kind of negative emotions is small in cancer patients, or when these emotions differ across the phases in the illness trajectory, this approach might not reliably detect all patients at risk. Supporting this notion, Mitchell et al. (2009) demonstrated that the addition of anxiety, depression and anger thermometers to the existing distress thermometer improved diagnostic accuracy.

The current study aims to examine the effect of different meaningful phases in the first year after a breast cancer diagnosis on anxiety, depressive symptoms and nonspecific distress. Specific attention will be paid to the implications of the resulting patterns for screening and the timing of psychosocial interventions.

3.2 Methods

Procedure

Recruitment was from six hospitals in the Northern part of the Netherlands. The study protocol was approved by all Medical Ethical Committees. Women who were referred to the hospital because of a suspicion of breast cancer, were invited to participate. Women were eligible if they (1) were 75 years old or younger, (2) did not have a serious psychiatric disorder or a somatic disorder that implied hospital admission, (3) comprehended Dutch, (4) followed the usual diagnostic protocol and (5) did not have a history of cancer. Women diagnosed with breast cancer were included in the patient group. Women diagnosed with no tumor, or a benign tumor that did not need to be surgically removed (mostly cysts), were included in the reference group as soon as a definite benign diagnosis was confirmed.

Design

The five assessments in the patient group were linked to clinically meaningful events: shortly after diagnosis, but before surgery (T1; on average 12 days after diagnosis); after surgery, but before the start of adjuvant treatment (T2; on average 51 days after diagnosis); right after adjuvant treatment (T3; on average 5.5 months after diagnosis); in the re-entry phase at 2 months after the end of radio- and or chemotherapy (T4; on average 7.5 months after diagnosis); and in short-term survivorship phase at 6 months after the end of complete treatment (T5; on average 11.5 months after diagnosis).

Each patient was matched to one woman in the control group of similar age (within a range of 5 years). The timing of the four assessments in the matched control group was chosen to resemble the timing of assessments in patients: right after diagnosis (T1; on average 19 days after diagnosis), 8 weeks after diagnosis (T2; on average 61 days after diagnosis) and at the same time since diagnosis as the matched patient received T4 and T5 (on average 7.5 months and 11.5 months after diagnosis). T3 was omitted in the reference group, to prevent overload.

Samples

A total of 3093 women referred to the hospital were invited to the study. Of these, 1226 gave informed consent prior to diagnosis, 1094 of which met the inclusion criteria. Of these 1094 women, 912 women could be contacted within 6 weeks after diagnosis and were willing to confirm their pre-diagnosis consent. Of these 912 women, 242 women were diagnosed with breast cancer and 670 were diagnosed with no or a benign tumor. As only patients treated with radiotherapy and/or chemotherapy went through all five stages of interest (diagnosis, surgery, adjuvant treatment, re-entry and short-term survivorship), we chose to exclusively focus our analysis on this majority (n = 203; 84%).

Of the 203 women treated with adjuvant therapy, 104 women (51%) participated at all occasions. The 99 women who missed one or more assessments, had missings that were either occasional (33%), due to drop out (10%) or both (5%, first occasional than drop out). The most common reasons for drop out in the patient group was that participation was considered too burdensome (50%). Occasional missed assessments often had to with time constraints in the period around diagnosis and surgery (T1, T2). Except for two women who missed the scales assessing negative affectivity at all occasions, the study includes both complete (n = 104) and incomplete cases (n = 97). These 201 women were largely similar to the regional population of women diagnosed with breast cancer and treated with adjuvant therapy with respect to age and cancer stage (Comprehensive Cancer Center North-Netherlands Cancer Registry, 2005).

Of the 201 patients, 194 were matched to a woman in the reference group. Of these women, 35 missed one or more assessments due to drop out. Reasons for drop out in the reference group were not systematically reported. Most women who did give a reason, mentioned a lack of time or interest. Based on these few accounts, our guess is that the study lost meaning over time for women who were not diagnosed with cancer. Table 3.1 shows the sample characteristics of patients as well as the reference group.

Instruments

Anxiety was assessed with the 6-item short version of the state scale of the Spielberger State and Trait Anxiety Inventory (Spielberger & Gorsuch, 1970; Marteau & Bekker, 1992; van der Bij et al., 2003). Respondents were asked to rate the degree to which they were currently experiencing each anxiety symptom on a 4-point scale ranging from (1) 'not at all' to (4) 'very much so'. The items reflect the presence (tense, upset, worried) or the absence of anxiety (calm, relaxed, content). Scores range from 6-24. Alphas ranged from .85 to .87. On the original 20-item scale, scores greater than 44 indicate high anxiety in a female population aged 40-59 (Spielberger & Gorsuch, 1970). This cut-off is used more often in cancer patients (Millar et al., 1995; Korfage et al., 2006). Transformation of this cut-off to the 6 items version results in a cut-off of >13.

Depressive symptoms were assessed with the Center for Epidemiologic Studies Depression scale (Schroevers et al., 2000; Radloff, 1977). Respondents rated how often they experienced each of 20 symptoms of depression during the past week on a 4-point scale ranging from (0) 'rarely or none of the time' to (3) 'most or all of the time'. Examples of symptoms are a poor appetite, concentration difficulties, inability to get going and feeling depressed. Scores range from 0-60.

Table 3.1 *Demographic and medical characteristics of the patient and the reference group*

		Patients	Reference group
Demographic characteristics			
Age M(SD; range)		55.0 (9.1; 31-74)	54.1 (8.4; 30-74)
Education %			
	Low	43%	47%
	Intermediate	34%	28%
	High	23%	25%
Children %		88%	84%
Children under 18 %		27%	22%
Paying job %		48%	53%
Partner %		88%	81%
Medical characteristics			
Stage %			
	0	6%	
	1	38%	
	2	45%	
	3	12%	
Positive nodes %		39%	
Mastectomy %		23%	
More than 1 surgery %		37%	
Adjuvant treatment RT/CT %			
	RT	49%	
	CT	13%	
	RT & CT	38%	

Alphas ranged from .87 to .91. Scores of 16 or greater indicate a clinically significant level of symptoms of depression (Radloff, 1977). In the general female population, 14-22% scores above this cut-off (Bouma et al., 1995).

Nonspecific psychological distress was assessed with the General Health Questionnaire. The questionnaire is designed to assess discontinuity in the respondent's usual state or in the usual level of functioning and was based on common elements of diverse types of psychopathology (Goldberg & Williams, 1988; Koeter & Ormel, 1991). Respondents were asked, for example, if lately they were able to concentrate on what they were doing, lost sleep over worries, felt they played a useful part in things, felt capable of making decisions or felt constantly under strain. Respondents were instructed to compare their present state with their usual state. The total scale score was calculated by counting the number of items for which respondents indicated a state that was 'worse' or 'much worse' than usual. Scores range from 0-12. Alpha's ranged from .88 to .92. Scores greater than 3 (conservative cut-off) indicate clinically significant levels of distress (Goldberg & Williams, 1988; Parle et al., 2001). In the general female population, 10-19% scores above this cut-off (Koeter & Ormel, 1991).

Analysis

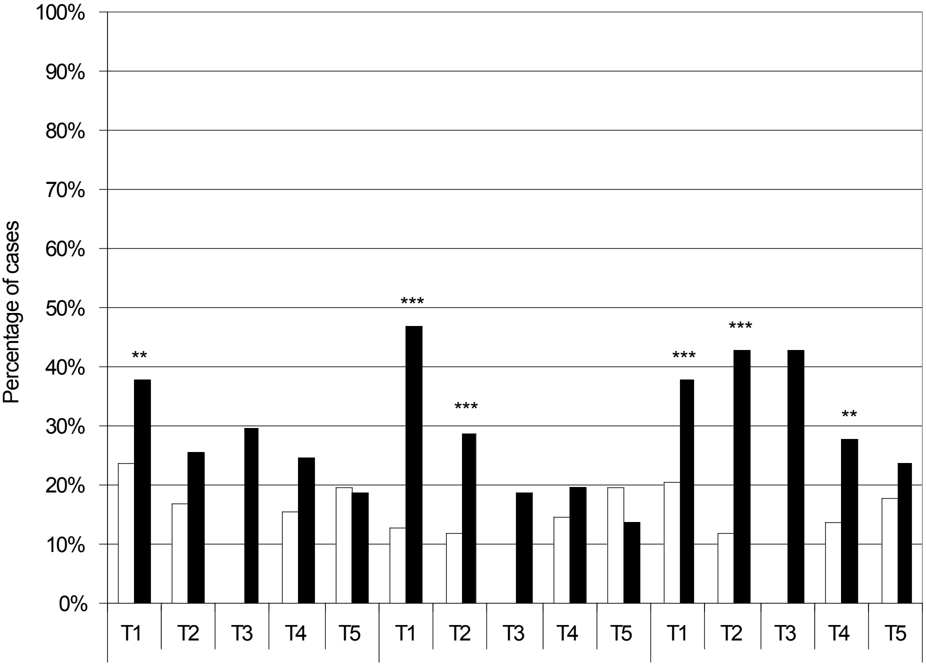
First, to determine the randomness of missing data, we examined whether the subset of patients with complete data differed (ES >= 0.2, small effect according to Cohen) from patients with incomplete data regarding the mean levels of the three indicators of psychological well-being at each time point. *Second*, to examine the overlap between the three indicators, we calculated the cross-sectional correlations at each assessment. *Third*, to determine if patients differed from the reference group regarding the course and/or the overall level of the negative emotions after diagnosis, an ANOVA repeated measures was performed for the three emotions separately, excluding T3 (as this assessment was omitted in the reference group). This analysis included cases with complete data on T1, T2, T4, T5 only. *Fourth*, when groups were shown to differ, we examined the confidence intervals and the sizes of group differences at each assessment separately to gain more insight in the differential effect of distinct phases in the first year. As the width of the confidence intervals depends on sample size (the larger the sample, the more precision, the narrower the CI), we made use of the full sample in these comparisons. We also examined between-group differences in the percentages of women with elevated levels on the three indicators (probable cases), using Chi-square tests. *Fifth,* in order to determine the implications for screening, we examined the extent to which women with elevated scores on one or more of the three emotions would have been missed with exclusive reliance on one of the measures.

Table 3.2 *Means, standard deviations, differences in group means, 95% confidence intervals and effect sizes*

		Patient group						Reference group				
		Complete cases		Incomplete cases		Total cases		Total cases		Differences*		
		Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Δ	95%CI Δ	ES
Anxiety	T1	13.5 (3.6)	102	13.6 (3.9)	44	13.5 (3.7)	146	10.0 (2.9)	192	3.5	2.8 to 4.2	1.1 (large)
	T2	11.5 (3.3)	102	11.9 (3.9)	69	11.7 (3.6)	171	10.0 (3.0)	187	1.7	1.0 to 2.4	0.5 (medium)
	T3	10.7 (3.2)	102	10.9 (3.5)	74	10.8 (3.3)	176					
	T4	10.6 (3.5)	102	11.0 (3.2)	75	10.8 (3.4)	177	10.2 (3.2)	174	0.6	-0.1 to 1.3	0.2 (small)
	T5	10.1 (3.0)	102	10.6 (2.8)	68	10.3 (2.9)	170	10.6 (3.5)	158	-0.3	-0.9 to 0.5	-0.1 (no)
Depression	T1	13.9 (8.0)	103	13.1 (10.6)	44	13.7 (8.9)	147	10.7 (8.8)	193	3.0	1.1 to 4.9	0.3 (small)
	T2	10.7 (7.5)	103	12.5 (9.2)	68	11.4 (8.2)	171	8.5 (7.8)	185	2.9	1.2 to 4.6	0.4 (small)
	T3	11.8 (8.9)	103	11.9 (8.7)	73	11.8 (8.8)	176					
	T4	10.3 (9.3)	103	10.5 (7.9)	74	10.4 (8.7)	177	9.0 (7.8)	174	1.4	-0.4 to 3.1	0.2 (small)
	T5	8.8 (8.6)	103	10.3 (7.9)	67	9.4 (8.3)	170	9.3 (8.6)	157	0.1	-1.8 to 1.9	0.0 (no)
Distress	T1	3.2 (3.1)	98	3.5 (3.2)	46	3.3 (3.1)	144	1.9 (3.0)	194	1.4	0.8 to 2.1	0.5 (medium)
	T2	3.4 (3.1)	98	4.1 (3.6)	72	3.7 (3.4)	170	1.3 (2.5)	187	2.4	1.8 to 3.0	0.8 (large)
	T3	3.1 (3.2)	98	3.9 (3.6)	78	3.5 (3.4)	176					
	T4	2.7 (3.6)	98	2.5 (3.2)	79	2.6 (3.4)	177	1.4 (2.8)	174	1.2	0.6 to 1.9	0.4 (small)
	T5	2.2 (3.5)	98	2.0 (3.1)	70	2.1 (3.3)	168	1.8 (3.2)	158	0.3	-0.3 to 1.1	0.1 (no)

* Difference between total reference group and total patient group at each assessment.

Figure 3.1 *Percentages of respondents with scores above the cut-off (probable cases)for depressive symptoms, anxiety and non-specific distress*



White = Reference group; Black = patient group
Chi-squared tests ** p < .01, *** p < .001

3.3 Results

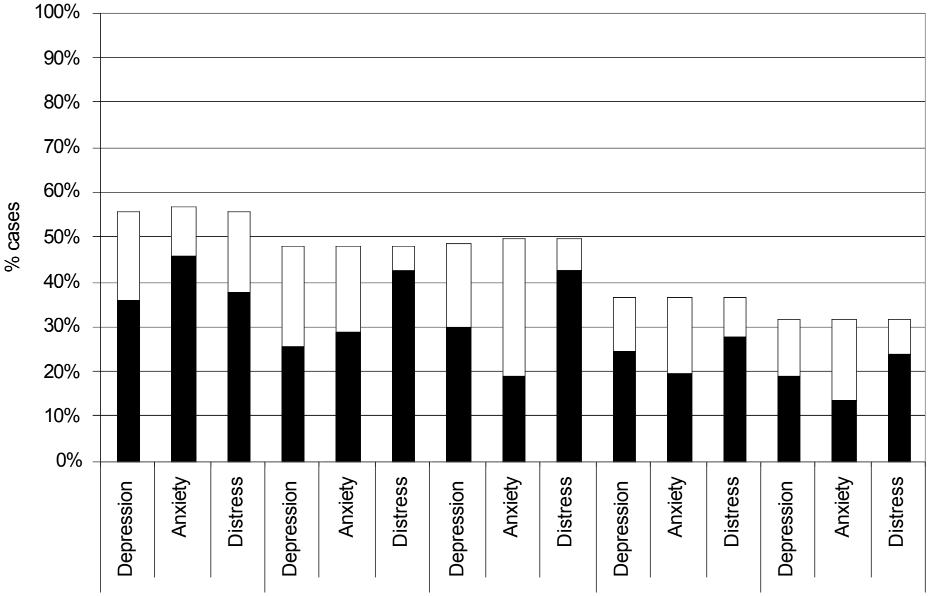
The subset of patients with complete data (T1-T5) did not differ from patients with incomplete data in terms of the mean levels of anxiety in each illness stage (Table 3.2). Women with incomplete data were somewhat more depressed at T2 (ES = 0.22) and somewhat more distressed at T2 (ES = 0.21) and T3 (ES = 0.24). None of these differences were statistically significant. We can conclude that, even though patients who missed assessments were rather similar to patients with complete data at the assessments they did complete, missings were possibly related to negative affectivity and might not be entirely random.

Across occasions (T1-T5), the correlations among the three measures under study ranged between .72 and .78 (anxiety-depression), .63 and .69 (anxiety-distress) and .71 and .79 (distress-depression) in the patient group, and respectively between .47 and .69, between .35 and .68 and between .59 and .71 in the reference group. These correlations indicate an overlap of about 50% in the variance of these measures in breast cancer patients. The overlap in the reference group was somewhat lower at baseline, but similar to that in patients at later assessments.

The ANOVA repeated measures analyses (excluding T3) demonstrated that the course of all three indicators (time x diagnosis) was different in patients compared to the reference group, $F_{anxiety}(3,257)= 29.2$, $p < .001$, $F_{depresssion}$ $(3,256) = 3.4$, $p = .02$, $F_{distress}(3,256) = 6.9$, $p < .001$. Moreover, the overall levels of anxiety, $F(1,259) = 14.4$, $p < .001$, and distress, $F(1,258) = 20.2$, $p < .001$, were higher in patients than in the reference group. This between-group difference was marginally significant for depressive symptoms, $F(1,258) = 3.5$, $p = .06$.

Subsequently, we examined the group differences at each point in time in more detail (Table 3.2). Even though the reference group was not assessed at T3, the assessment was included in Table 3.2 and in the interpretation of the results regarding the course of the negative emotions. As becomes clear from the effect sizes and confidence intervals, group differences between patients and the reference group on *anxiety* were large right after diagnosis (T1) and still of medium size after surgery (T2). During adjuvant treatment, as well as in the re-entry and survivorship phase (T4, T5), these differences disappeared. In contrast to anxiety, the effect of a breast cancer diagnosis on *depressive symptoms* was fairly small in the early phases (T1-T2). Moreover, in the re-entry and survivorship phase (T4 and T5), patients did not differ at all from the reference group. Lastly, *nonspecific distress* was highest right after surgery (T2) and right after adjuvant treatment (T3),

Figure 3.2 *Identification of patients with scores above the cut-off (probable cases) on one or more of the three indicators by each of the indicators separately*



White = not identified; Black = identified

The percentage of total probable cases differs across measures due to rounding differences (<= 1%).

still somewhat elevated in the re-entry phase (T4), yet normalized six months after the end of treatment (T5). Figure 3.1 shows the percentage of women with elevated levels (probable cases) on the three indicators. These results show a similar pattern as the course of the mean levels.

Figure 3.2 shows the percentages of patients with elevated scores (above the cut-off) on one or more of the three emotions (probable cases), as well as the percentage of these identified by each of the three indicators. The percentage of probable cases decreased from 56% at T1 to 32% at T5. Some, but not all probable cases had elevated scores on all three indicators (43% at T1, 28% at T5; not in figure), which has implications for the practice of screening. The figure shows that screening for anxiety might be the best way to detect women with probable problems right after diagnosis (46% was identified). However, at later assessments, screening for anxiety would detect fewer cases than the other two indicators, missing more than half of them at T3. Particularly during treatment (T2 and T3), but also after treatment, screening for distress seems to detect most women with a possible need for psychosocial care.

3.4 Discussion

Even though correlations between depressive symptoms, anxiety and nonspecific distress confirmed that negative emotions are often experienced simultaneously, the various phases after a breast cancer diagnosis differentially triggered these emotions. The initial response right after diagnosis was mostly characterized by *anxiety*, which decreased to a level similar to that in the reference group in later phases. This result is in line with the theoretical assumption that anxiety is triggered by threat and imminent danger (Finlay-Jones & Brown, 1981). Uncertainty in later stages, for example about recurrence, did not seem to cause high anxiety levels. Possibly, such uncertainty is reflected in more cancer-specific fears and worries. Compared to women not diagnosed with breast cancer, *depressive symptoms* were only somewhat elevated in women with breast cancer and decreasing over time. This result is not in line with claims that depression is a frequent emotional response in cancer patients (Massie, 2004) nor with sometimes suggested increase in depressive symptoms in later stages after a cancer diagnosis (Nosarti et al., 2002), yet it does confirm earlier findings of higher rates of anxiety compared to depressive symptoms in women with breast cancer (Montazeri et al., 2000). Possibly, women with newly diagnosed breast cancer who are treated with curative intent are not dealing with many or intense loss experiences that trigger sadness (Finlay-Jones & Brown, 1981). Lastly, *nonspecific distress* was elevated in all phases, mostly right after surgery, and was only decreasing to the level in the reference group in the short-term survivorship phase. This result seems to indicate that the negative affect cancer patients experience is of a more general kind. Even though nonspecific distress includes symptoms of anxiety and depression, items also asked about the ability to face problems or about feeling under strain.

The extent to which these results are determined by the specific questionnaires used warrants discussion. First of all, the finding that distress in women with breast cancer is elevated in all but the last illness phase when compared to the reference group might be a result of the format of the GHQ, i.e. asking patients to compare the present state with the usual state. This format forces a before-after comparison, which might have triggered respondents to report a negative change. In future studies with a similar design, including a questionnaire assessing nonspecific distress with a more neutral format could provide insight in this matter. Second, possibly the difference between anxiety and depressive symptoms is prominent in this study because two different questionnaires were used to assess the two concepts. Unpublished results on longitudinal data of women with breast cancer that included the Hopkins Symptom Checklist-25, consisting of both anxiety and depression items, showed similar patterns of both emotions (personal communication Steve Palmer, University of Pennsylvania). Interspersed items and identical response keys of this questionnaire might have resulted in a more general response strategy, which might have masked differences between the constructs. Future studies should examine if using distinct questionnaires is advisable when one aims to make a clearer distinction between different negative emotions.

The distinct trajectories have implications for the practice of screening and psychosocial interventions. With respect to screening, our study findings support the conclusion of Mitchell et al. (2009) that a screening instrument that covers several emotional domains might be more sensitive to fluctuations in the type of negative emotions than an instrument focusing on only one. Right after diagnosis, screening patients for anxiety will identify the most patients at risk. In all later phases, but particularly during treatment, screening for elevated nonspecific distress levels will detect most patients with elevated negative affect, as in these phases women with elevated levels of anxiety and depression, often also had elevated levels of distress (yet, not the other way around). With respect to interventions, our findings show that psychosocial interventions offered in various phases after diagnosis should take into account that the types of negative emotions differ across these periods, as different emotions might ask for different types of interventions. For example, interventions delivered very shortly after diagnosis might work best if they focus on relieving anxiety, by for example education or relaxation exercises. Furthermore, intervention researchers should bear in mind that negative emotions often resolve naturally over time. This does not imply that interventions can not relieve psychological suffering in the early phases after diagnosis, yet it does have implication for the assessment of the effectiveness of interventions and asks for an RCT design.

Despite several strengths, i.e., a longitudinal case-control design linking assessments to clinically meaningful stages, the current study has limitations as well. First of all, compared to women with complete data, women with incomplete data reported more distress and depression than women without missings at some occasions on which they did participate. Even though these differences were small and non-significant, they do indicate that missings might not have been completely random (as in most psychosocial studies) and, although speculative, women who missed an assessment might have experienced more negative emotions on that occasion than women who did not. Second, the confrontation with a suspicion of breast cancer and, in some cases, with the diagnosis of a benign breast disease might have affected emotions in women in the reference group, which might compromise use of this group as a reference group. The somewhat elevated levels of negative emotions at T2 indicate that women were not immediately reassured after the good news. However, from T2 on, the percentages of probable cases of depression and distress in the reference group seem to fall in the range of percentages found in the general female population (14-22% for depression; 10-19% for distress) and remain rather stable thereafter, indicating that the impact of the benign diagnosis has subsided. Lastly, even though the assessments two and six months after the end of radio- and or chemotherapy (T4 and T5) were named the re-entry and short-term survivorship phase, this does not mean that women did not receive any treatment at all in this period. Of the 201 women, 47% was treated with hormonal therapy, which in most cases implies self-administration of medication for several (usually five) years. Moreover, 13% of women were treated with trastuzumab (Herceptin), a medicine delivered through an infuse every three weeks for a period of 1 year, often starting after chemotherapy treatment. Because of their considerable duration, it was decided not to take these treatment modalities into account in the design. Findings regarding the distinct trajectories in the three indicators of negative affect were not different when the 14% of women treated with trastuzumab, by far the most intensive modality of the two, were excluded.

In sum, the current study shows that distinct phases after a breast cancer diagnosis, which are each characterized by different stressors, trigger different types of negative emotions. Future research on psychological adjustment to cancer should take these differences between meaningful phases and different emotions into account. Accumulative insights in distinct trajectories of negative emotions might eventually direct the timing and content of psychosocial screening as well as the tailoring of psychosocial interventions.

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Chapter 4

The sooner, the better? Psychological consequences of waiting in breast disease clinics

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Summary

Objective. Examine the effect of diagnostic speed and the waiting period before surgery on psychological well-being of patients in breast disease clinics.

Methods. Women with a suspicion of breast cancer completed questionnaires about their psychological well-being before the first clinic visit (T1), shortly after diagnosis (T2) and 2-3 months later (T3). Two months after the end of treatment (T4), women with breast cancer indicated which period they considered most stressful in retrospect. Diagnostic speed and the waiting period before surgery were categorized. Analyses were controlled for age and cancer stage.

Results. Although the period before diagnosis was experienced as stressful, diagnostic speed did not affect emotional well-being after a breast cancer diagnosis. A diagnosis that took long (>2 weeks) did affect the emotional well-being of women who were not diagnosed with breast cancer. These women were worried and distressed for a longer period of time after diagnosis than women who received the good news sooner. The length of the waiting period before surgery did not affect the emotional well-being of patients thereafter. Women who had surgery within two weeks were not worse or better off than women who had to wait longer. Yet, patients' emotional well-being did improve considerable after surgery, which indicates that short waiting periods might shorten the stressful pre-surgery period.

Conclusions. The results advocate a speedy diagnosis and surgery. There was no support for a therapeutically overwhelming effect.

Numbering of assessments in this chapter compared to numbering in original design (Figure 1.1)

Chapter 4	T1-T3	T4
Original design	T1-T3	T5

4.1 Introduction

The length of waiting periods is becoming an increasingly important indicator of the quality of care in breast disease clinics (www.snellerbeter.nl). Dutch guidelines now provide explicit standards with regard to the length of the diagnostic period and the start of treatment after a breast cancer diagnosis (Nationaal Borstkankeroverleg Nederland, 2008). Yet, do short waiting periods always benefit the patient?

Waiting in breast disease clinics has a number of negative *medical*, *social* and *psychological* consequences. First of all, a late start of treatment can negatively affect prognosis (Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999; Kievit, 2002). Furthermore, long waiting periods imply that patients will not be able to fulfil their social roles for a long period of time (Oudhoff, Timmermans, Knol, Bijnen, & van der Wal, 2007). Lastly, long waiting periods are often assumed to cause stress and a decline in emotional well-being (Signaleringscommissie Kanker van KWF Kankerbestrijding, 2006). Little empirical research has, however, addressed such psychological consequences of waiting. A number of non-Dutch studies showed that a fast diagnosis positively affects the well-being of women who were not diagnosed with a malignancy (Ubhi et al., 1996; Harcourt, Rumsey, & Ambler, 1999), but might have an unfavorable effect on women diagnosed with breast cancer (Harcourt et al., 1999). Waiting for diagnosis as well as for the subsequent surgical intervention might give patients time to adapt to and prepare for what's coming (Kievit, 2002).

The current study aims to examine the psychological consequences of waiting in breast disease clinic. Four questions were addressed: (1) Does a suspicion of breast cancer result in psychological complaints and worries? (2) Do changes in complaints and worries after diagnosis depend on diagnostic speed? (3) Do changes in psychological complaints, anxiety and depressive symptoms after surgery depend on the waiting period before surgery? (4) Which period do patients consider most stressful in retrospect and does this rating depend on speed?

4.2 Methods

Sample and design

Six hospitals in the Northern part of the Netherlands were involved in the recruitment of respondents from December 2005 until March 2007. Women who were referred to the hospital because of a suspicion of breast cancer were invited by mail to participate in a longitudinal psychosocial study (Figure 4.1). Women were eligible if they were 75 years old or younger, comprehended Dutch, did not have a history of cancer, were treated with surgery and not with neo-adjuvant chemotherapy after a breast cancer diagnosis, and were not treated with surgery when no malignancy was found. A total of 242 women with breast cancer and 670 women with no malignancy were included. Known reasons for non-response were a lack of interest or the perception that participation was too burdensome.

Figure 4.1 *Flow chart*

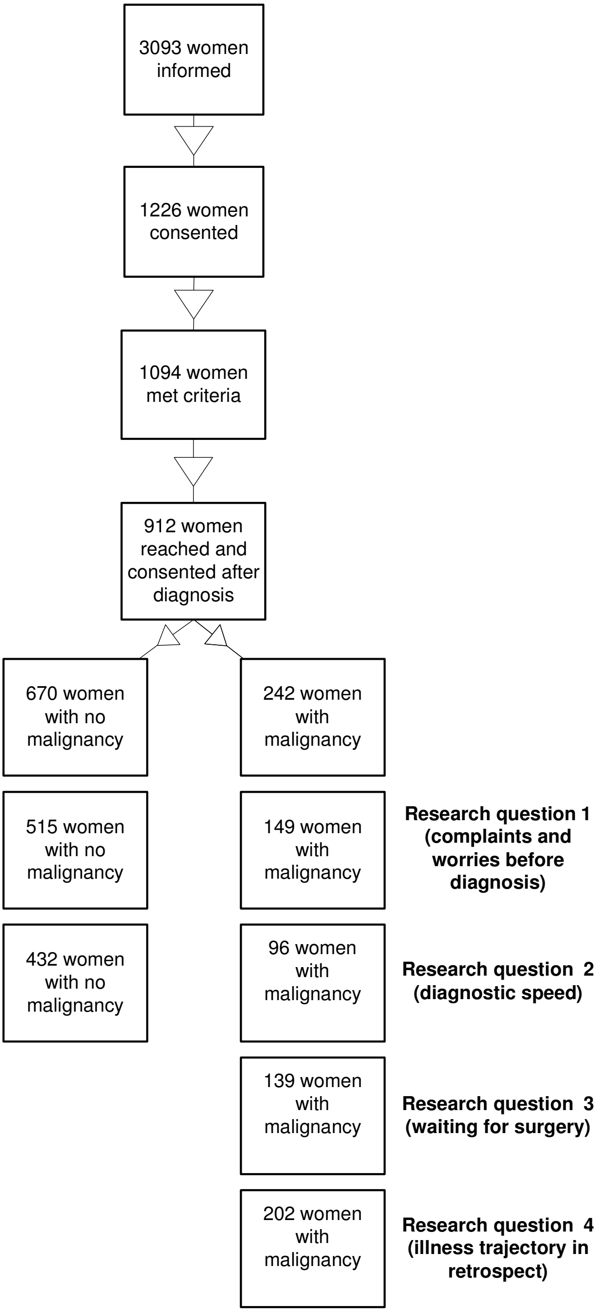

Figure 4.2 *Time line with the questionnaires completed at each assessment*

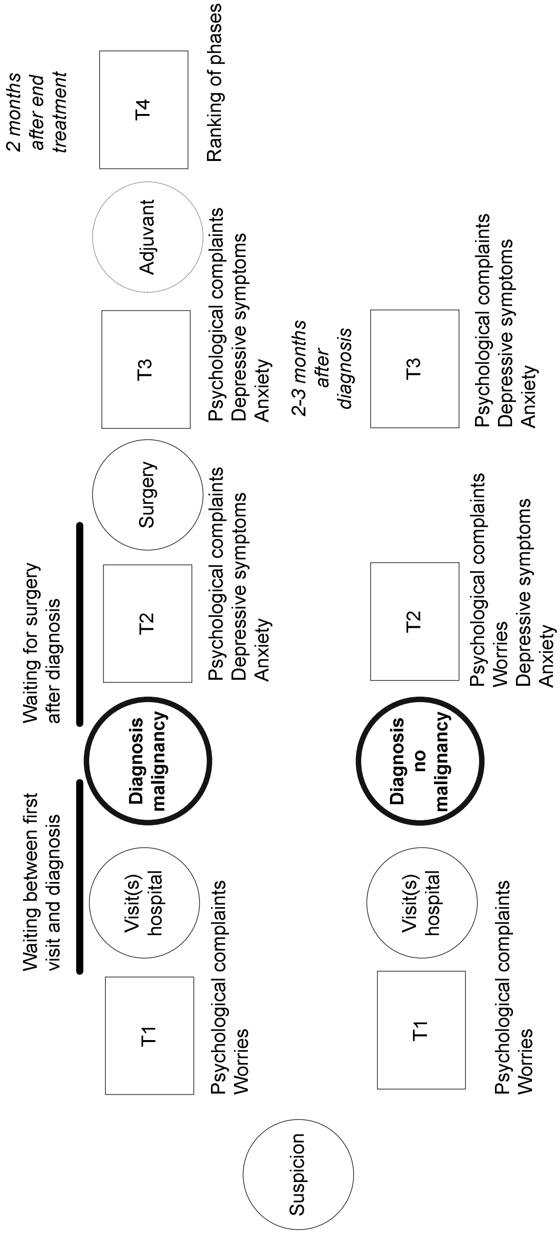

Figure 4.1 shows the number of patients included in the analyses for each research question and Figure 4.2 shows the research design. The questionnaire before the first visit to the hospital (T1; *research question 1*) was not completed by all participants, often due to the short waiting period after referral. One hospital completely omitted the T1 assessment for that reason. Women who were not informed prior to the first hospital visit, were informed in the hospital. Missing T1 was not related to well-being on later assessment points, irrespective of diagnosis.

Similar to the time between referral and first visit to the hospital, the time between the diagnosis of breast cancer and first surgery (T2), as well as between last surgery and the start of adjuvant therapy (T3) was often short. As a result, questionnaires could not be completed in time by all patients. Furthermore, there was some drop out, because of a decrease in interest over time (women without breast cancer) or due to the perception that participation was too burdensome (women with breast cancer). Women with complete data (T1-T3; *research question 2*) did not differ from women with incomplete data regarding the length of the waiting period before diagnosis or psychological well-being, irrespective of diagnosis.

Women with breast cancer who had complete T2-T3 data (*research question 3*) did differ from women with incomplete data on psychological well-being. Women who missed the questionnaire before surgery (T2), reported more psychological complaints after surgery (T3). The period between diagnosis and surgery was also shorter for these women. It is unclear whether the fast surgery is causally related to the high number of complaints afterwards. Probably, two independent reasons for missing T2 play a role, i.e., a lack of time to fill out the questionnaire due to a fast surgery and the presence of psychological complaints already before surgery.

Women with breast cancer who completed a questionnaire after the end of treatment (T4) also differed from women who did not with respect to psychological well-being (*research question 4*). Women who missed the T4 assessment (dropped-out) reported more depressive symptoms at T3 than women who did not. Missing T4 was however not related to the length of the waiting period before diagnosis or surgery.

Diagnostic speed and waiting period before surgery

Three categories of diagnostic speed were distinguished, i.e., (1) at the same day, (2) within 2-14 days after the first visit to the clinic, (3) more than 14 days later. Among women with breast cancer (research question 2) the distribution over these categories was respectively 47%, 41% (median one week) and 13% (median 3 weeks). Among women without a malignancy the distribution was 78%, 14% (median 1 week) and 8% (median 3 weeks) respectively.

The waiting period before surgery was categorized in: (1) less than 2 weeks after diagnosis, (2) within 2-3 weeks and (3) more than 3 weeks. The distribution over these categories (research question 3) was 31% (median 11 days), 35% (median 17 days) and 35% (median 25 days) respectively.

Data collection

General *psychological complaints* were assessed with the 12-item version of the General Health Questionnaire (Goldberg & Williams, 1988; Koeter & Ormel, 1991). The higher the score (0-12) is, the more complaints one has. The cut-off for possible psychological problems in the general population is a score of 2 and higher. Among women in the general Dutch population 26 % scores above this cut-off (Verhaak, Hoeymans, Garssen, & Westert, 2005). *Worries* were assessed before diagnosis (T1), and among women without a malignancy also after diagnosis (T2), with the Cancer Worry Scale (Lerman et al., 1991). The three items ask about the frequency of worries regarding one's chance of having breast cancer and the extent to which these worries were affecting mood and daily activities (1-4). A higher scale score (3-12) indicates more worries. *Depressive symptoms* were assessed after diagnosis only (T2-T3), with the 20-item Center for Epidemiologic Studies Depression scale (Radloff, 1977; Schroevers, Sanderman, van Sonderen, & Ranchor, 2000). A higher score (0-60) indicates more symptoms. *Anxiety* was assessed after diagnosis only (T2-T3), with the 6-item version of the Spielberg State and Trait Anxiety Inventory (Spielberger & Gorsuch, 1970; Marteau & Bekker, 1992), completed with one extra item. A higher score (7-28) reflects more anxiety. In a face to face interview 2 months after the end of treatment (T4) women with breast cancer ranked cards with the different stages of the illness trajectory, putting the most stressful stage on top.

Analyses

Differences in group means were tested with analysis of variance (ANOVA). Group differences in changes over time were tested in analysis of variance for repeated measurements. The effect sizes of differences in raw group means were indicated by Cohen's d (Cohen, 1992; small d = 0.2; medium, d = 0.5; large, d = 0.8)[16]. The relation between on the one hand ranking the stage before diagnosis or the stage before surgery as the most stressful (yes or no) and on the other hand the length of the waiting period before diagnosis or surgery was tested in two logistic regression analyses. The shortest waiting period was the reference category.

A lower age (irrespective of diagnosis) and a higher cancer stage (based on TNM classification) were related to a shorter waiting period before diagnosis, but not to the length of the waiting period before surgery. Age and cancer stage were included in all analyses regarding the effect of diagnostic speed (research question 2 and 4).

4.3 Results

Psychological complaints and worries before diagnosis

Before diagnosis, women reported on average 2,5 out of the 12 possible psychological complaints, independent of the eventual diagnosis (Table 4.1). A total of 45% scored above the cut-off for psychological problems (versus 26% in

Table 4.1 *Psychological complaints and worries before diagnosis (T1)*

	Total (n = 664)	Malignancy (n = 149)	No malignancy (n = 515)
Psychological complaints			
Mean (SD)	2.5 (3.1)	2.3 (3.0)	2.5 (3.2)
% above cut-off (>=2)	45%	44%	46%
Worries over chance cancer			
Mean (SD)	2.2 (0.8)	2.3 (0.8)	2.1 (0.8)[a]
% 'often' or 'almost always'	28%	38%	26%
Effect worries on mood			
Mean (SD)	1.7 (0.7)	1.7 (0.8)	1.7 (0.7)
% 'often' or 'almost always'	13%	14%	13%
Effect worries on activities			
Mean (SD)	1.3 (0.6)	1.4 (0.6)	1.3 (0.6)
% 'often' or 'almost always'	5%	5%	5%

[a] Mean is significantly different from the mean in the patient group (malignancy), controlled for differences in age, F (1,661) = 11.826, p < .01.

the general population). Before diagnosis, over a quarter of the women were often or almost always worried about their chances of having breast cancer. Women who were eventually diagnosed with a malignancy, reported more worries already before diagnosis (small effect, d = 0.25). For most women, these worries had little effect on their mood or daily activities.

Effect of diagnostic speed

Psychological complaints increased after the diagnosis of breast cancer (T2) and remained elevated after surgery (T3), independent of diagnostic speed (Table 4.2). In contrast, when no malignancy was found, changes in complaints were related to diagnostic speed. Women who received the favourable diagnosis at the same day, did not differ from women who were diagnosed within two weeks. However, women who had to wait for more than two weeks, showed a temporal peak in complaints (difference with two other categories on T2: d = 0.5), which disappeared only 2-3 months later (T3). Similar to complaints, worries also immediately decreased in women who received the diagnosis at the same day, but remained elevated in women who had to wait for a maximum of two weeks (difference with a same day diagnosis on T2, d = 0.4) and increased in women who had to wait for more than two weeks (difference with a same day diagnosis on T2, d = 0.7).

Effect of the waiting period before surgery

After surgery, general psychological complaints did not change, while anxiety

Table 4.2 *Effect of diagnostic speed on changes in psychological complaints and worries (T1-T3)*

	Before diagnosis	After diagnosis		
	T1 [a]	T2	T3	n
Malignancy				
Psychological complaints (0-12), M (SD)[b]	2.3 (3.1)	3.5 (3.4)	3.3 (3.0)	96
Same day	2.4 (3.3)	3.5 (3.5)	3.3 (3.4)	45
<= 2 weeks	2.4 (3.1)	3.5 (3.5)	3.3 (2.9)	39
> 2 weeks	1.6 (2.2)	3.3 (2.8)	3.3 (2.2)	12
No malignancy				
Psychological complaints (0-12), M (SD)[c]	2.5 (3.2)	2.1 (3.1)	1.6 (2.9)	432
Same day	2.5 (3.2)	2.0 (3.0)	1.7 (2.9)	336
<= 2 weeks	2.1 (3.0)	1.9 (2.8)	1.5 (2.8)	60
> 2 weeks	2.5 (3.8)	3.5 (3.1)	1.7 (3.2)	36
Worries chance cancer (3-12), M (SD) [d]	5.2 (1.8)	4.6 (1.8)		432
Same day	5.2 (1.9)	4.4 (1.7)		336
<= 2 weeks	5.1 (1.6)	5.0 (1.8)		60
> 2 weeks	5.1 (1.9)	5.6 (2.4)		36

[a] Groups were not different at T1; [b] Ftime x speed (4,182) = 0.656 , p = .62; [c] Ftime x speed (4,856) = 3.463, p <. 01; [d] Ftime x speed (2,428) = 9.729, p < .001; T1 before first visit, T2 directly after diagnosis, T3 after surgery for breast cancer or 2-3 months after a favorable diagnosis (no malignancy)

and depressive symptoms decreased, independent of the length of the waiting period (Table 4.3).

The illness trajectory in retrospect

In retrospect, half of the patients considered the period before the definite diagnosis the most stressful relative to the other stages in the illness trajectory (Table 4.4). One out of five women put the period before surgery on top. Diagnostic speed could not predict whether women considered the period before diagnosis as the most stressful (within 2 weeks, odds ratio = 1.34, p = .30; longer than two weeks, odds ratio = 0.83, p = .74) . The length of the waiting period before surgery could not predict whether women considered the period before surgery as most stressful either (2-3 weeks, odds ratio = 0.73, p = .47; longer than 3 weeks, odds ratio = 1.30, p = .53).

4.4 Discussion

Does a speedy diagnosis benefit the patient? The suspicion of breast cancer resulted in worries and an increased number of psychological complaints, irrespective of

Table 4.3 *Effect of waiting for surgery on changes in psychological complaints, anxiety and depressive symptoms (T2-T3)*

		Before surgery T2 [a]	After surgery T3	n
Psychological complaints (0-12), M(SD)[b]		3.4 (3.3)	3.3 (3.2)	139
	<=2 weeks	2.9 (2.7)	3.5 (2.8)	43
	2-3 weeks	3.5 (3.5)	3.1 (3.3)	48
	> 3 weeks	3.6 (3.5)	3.4 (3.5)	48
Anxiety (7-28), M(SD)[c]		15.4 (4.5)	13.1 (4.1)	139
	<=2 weeks	15.2 (4.5)	12.7 (3.7)	43
	2-3 weeks	15.9 (4.8)	13.5 (4.6)	48
	> 3 weeks	15.0 (4.4)	13.0 (3.9)	48
Depressive symptoms (0-60), M(SD)[d]		13.9 (9.5)	11.0 (8.5)	139
	<=2 weeks	13.1 (9.4)	10.7 (7.7)	43
	2-3 weeks	14.3 (9.9)	10.9 (9.5)	48
	> 3 weeks	14.3 (9.3)	11.4 (8.3)	48

[a] Groups did not differ at T2; b Ftime x waiting period (2,136) = 1.570 , p = .21; c Ftime x waiting period (2,136) = 0.243, p = .79; d Ftime x waiting period (2,136) = 0.304, p = 0.74; T2 directly after diagnosis, T3 after surgery, before start adjuvant therapy;

the eventual diagnosis. When no malignancy was found, changes post-diagnosis were found to be dependent on diagnostic speed. Right after diagnosis, worries decreased immediately only if the diagnosis was communicated at the same day. Furthermore, psychological complaints and worries temporarily increased after diagnosis when the diagnostic period took longer than two weeks. In sum, a speedy diagnosis shortens a stressful period for women who turn out not to have breast cancer and prevents a delayed decrease in complaints and worries after such good news.

After a breast cancer diagnosis, psychological complaints strongly increased, independent of diagnostic speed. Yet, in retrospect, most women considered the period before diagnosis as the most stressful in comparison to the various stages after diagnosis. In sum, a fast diagnosis neither prevents nor promotes the increase in psychological complaints after bad news, but does shorten a period which many patients considered stressful.

Does a speedy surgery benefit the patient? The completion of the surgical treatment resulted in a decrease in anxiety and depressive symptoms, independent of the waiting period before surgery. Furthermore, in retrospect, the period before surgery was considered stressful more often than later periods in the illness trajectory. In sum, even though the improvement in emotional well-being after surgery did not depend on the waiting period, an early surgery did lead to an earlier improvement in well-being.

Table 4.4 Most stressful period in retrospect (T4)

Description of periods	Most stressful period				
	No adjuvant treatment[a] n= 34	Radiotherapy n = 78	Chemotherapy n = 21	Both radio- and chemotherapy n = 69	Total n = 202
The period before definite diagnosis (suspicions, GP, tests in hospital)	53%	60%	62%	44%	54%
The period right after diagnosis (diagnosis just known, waiting for surgery)	24%	13%	19%	26%	20%
The period before surgery(-ies) (discussion of treatment, recovery, removal plasters)	18%	19%	0%	12%	14%
The period of radiotherapy		4%		1%	2%
The period of chemotherapy			14%	15%	6%
First weeks after treatment in the hospital (radio/chemo)	3%	1%	0%	1%	2%
Now, several months after the end of treatment	3%	3%	5%	1%	3%

[a] Radio- and/or chemotherapy

Limitations

The dataset was suitable for a study on the consequences of waiting in breast disease clinics. Data on both pre- and post-diagnosis emotional well-being are rare. Yet, the study did not have a randomized design with a short and long waiting period condition. For this reason, there might be confounding variables which were not included in the study, but which are related to both the length of waiting periods and emotional well-being. In the current study, we could control for the possible confounding influence of age and cancer stage. A second limitation was the low response. A response of 40% (33% was also reached and consented after diagnosis; total malign and benign) is not unusual for longitudinal psychosocial studies among patient populations. Moreover, the 242 women with breast cancer were comparable to the regional population of women with breast cancer with respect to age, cancer stage and treatment (Dutch Cancer Registry, Comprehensive Cancer Center North Netherlands). A third limitation was the large number of women with missing data on the first two assessments. Even though some missings were related to length of waiting periods as well as to indicators of emotional well-being, it is less likely they affected the reported relations between the two (Crawford, Tennstedt, & McKinlay, 1995). Lastly, a fourth limitation was the lack of information regarding the time between referral and first visit to the hospital. This period does add to the total waiting period before definite diagnosis. For this reason, the current study allows for conclusions regarding the effect of diagnostic speed in breast disease clinics only.

Implications

Women who had to wait longer than two weeks for good news, reported more worries and complaints after diagnosis than before the first visit to the hospital. Probably these complaints and worries gradually increased during the period of waiting and the eventual favorable outcome did not result in immediate reassurance. Future qualitative research should address the reasons for this delayed decrease and the potential role of patient education in resolving these worries. The earlier reported finding that a speedy diagnosis results in more depressive symptoms some weeks after a breast cancer diagnosis was not replicated (Harcourt et al., 1999). We also did not find support for a 'therapeutically overwhelming' effect of a speedy surgery (Kievit, 2002). However, future qualitative research could provide more insight in how women experience short or long waiting periods before surgery, taking individual differences into consideration. The authors believe that, if medically allowed, the whishes of the individual patient should be taken into account when planning treatment and that the desirability of hurry should be discussed.

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Part 2

Perceived personal control and psychological adjustment

Chapter 5

Personal control after a breast cancer diagnosis: stability and adaptive value

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Summary

*Objective***.** This longitudinal study aims to gain more insight in both the changes in personal control due to a breast cancer diagnosis, as well as in the stress-buffering effect of personal control.

Methods. Personal control and distress were assessed in breast cancer patients not treated with chemotherapy (n = 47), breast cancer patients treated with chemotherapy (n = 32) and in healthy women (n = 58) at 3, 9 and 15 months after diagnosis.

Results. Results indicate that personal control was affected only in patients treated with chemotherapy, particularly right after the completion of treatment. Furthermore, the cross-sectional and longitudinal results provide modest support for the stress-buffering potential of control.

Conclusions. The findings and future directions of research on the role of personal control in the adjustment to cancer will be discussed.

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5.1 Introduction

Women diagnosed with breast cancer are confronted with different stressors throughout the illness trajectory, e.g., awaiting diagnosis, having surgery, anticipating the possibility that the cancer has spread, coping with side effects, and, finally, facing the risk of recurrence. Despite the uncertain and uncontrollable character of these stressors, personal control is generally believed to be an important resource for successful psychological adjustment.

Personal control refers to the belief that life is not ruled by fate, but that one is personally able to influence the important events or situations in life. This belief is consistently shown to be related to a variety of positive outcomes, such as a lower risk of disease (Bosma et al., 2005), successful adjustment to illness (Helgeson, Snyder, & Seltman, 2004) and even survival (Surtees, Wainwright, Luben, Khaw, & Day, 2006). Although a sense of control is largely shaped by personality, overwhelming aversive events challenge control perceptions. Yet, it is especially in the face of overwhelming negative events that personal control might constitute a stress-buffering resource.

The first aim of this study is to examine whether personal control changes after a breast cancer diagnosis. The surprisingly few studies that examined the impact of a cancer diagnosis on personal control yielded mixed results (Ormel et al., 1997; Penninx et al., 1996). Most studies were cross-sectional and time passed since diagnosis varied greatly. As a consequence, it remains unclear at what point in time changes in personal control occur and if changes are permanent or temporary in nature. Additionally, most studies did not take differences in the stressors faced after diagnosis into consideration. The present study adopts a longitudinal case-control design and takes into account the impact of chemotherapy on control perceptions. Chemotherapy is prescribed when prognostic characteristics are relatively unfavorable, i.e., the tumor is larger, more aggressive or has spread to the lymph nodes. Moreover, chemotherapy causes unpleasant side effects and increases treatment duration considerably. For these reasons, it is expected that the prescription of chemotherapy poses a substantial threat to control perceptions throughout the illness trajectory.

The second aim of this study is to examine the stress-buffering effect of personal control in women with breast cancer. Several researchers suggested that the adaptive value of a basic sense of control over life increases in stressful circumstances, but studies that actually test this assumption are scarce. A high sense of personal control might have stress-buffering potential in women with breast cancer, as it fosters effective *coping strategies* (Lazarus & Folkman, 1984), determines the way *social support* is used (Sandler & Lakey, 1982), influences the way the situation is *appraised* (Folkman, 1984), and promotes positive *attributions* about one's own role in limiting the negative impact of the disease (Hobfoll & Walfisch, 1986).

In conclusion, the current study aims to explore the two-sided position of personal control in the stress process (Pearlin & Skaff, 1996). It is hypothesized that personal control is affected by the various stressors women with breast cancer face (*Aim 1*), but that a sense of control also regulates the impact of the disease (*Aim 2*).

5.2 Method

Procedure and sample

The data used were part of a larger dataset that was collected in a longitudinal study on dyadic coping with cancer. The Medical Ethical Committees of the 5 participating hospitals approved the study protocol. Newly diagnosed breast cancer patients were included if 1) they had a partner willing to participate; 2) they were between 30 and 75 years old; 3) their survival prognosis was at least 15 months; 4) both partners had no previous history of cancer and 5) they both understood Dutch. Women in the reference group were selected from the register office of several townships and were matched to patients on the basis of age and region. Only women without a history of cancer and with a partner willing to participate were included (n = 64).

For the present manuscript, only the data of women were examined. Informed consent was obtained from 92 patients (32% response rate). Hinnen et al. (2007) reported results based on the same data and presented detailed information on response and refusal. Participants did not differ from non-participants with respect to age and region of residence. The current study reports on data collected at 3, 9, and 15 months post-diagnosis. After the deletion of drop-outs and incomplete cases (13 patients, 6 healthy women), the complete data of 58 healthy women and 79 patients, were available for analysis. Drop-outs and non-completers generally reported less mastery and/or more distress than completers at the various occasions, although none of these differences were significant.

Instruments

Personal control was assessed with the 7-item Mastery List (Pearlin & Schooler, 1978), which reflects perceived control over events and problems in life. The alphas range from .70 to .80. *Psychological distress* was assessed with the 12-item version of the General Health Questionnaire (Goldberg & Williams, 1988). Item scores were dichotomized conform the CGHQ scoring method of Goodchild and Duncan-Jones (1985). Compared to the original way of scoring, this method gives a more accurate index of a subject's present state. Alphas are higher than .80. Social-demographic characteristics included *age, educational level,* and two types of *co-morbidity* (the number of diseases present in the past 12 months treated or not treated by a medical specialist).

Analysis

Three groups were distinguished: healthy women (n = 58), breast cancer patients not treated with chemotherapy (CT; n = 47) and breast cancer patients treated with CT (n = 32). To examine if and when a breast cancer diagnosis affects perceptions of personal control (*Aim 1*), an ANOVA repeated measures was performed. Cohen's d based on within or between group differences in raw means will be presented to indicate effect size (ES).

To examine the relationship between personal control and distress (*Aim 2*), three cross-sectional regression analyses were performed. Possible confounders were entered in the first step. Two dummy variables contrasting the two patient groups with the reference group were entered in the second step, followed by personal control in the third step. Two interaction terms (dummy x personal control) were entered in the final step. A significant negative coefficient for an interaction term provides supports for a stress-buffer effect. R^2 will be presented for each step to indicate effect size.

The longitudinal control-distress relationships were examined as well, once with control at 3 months post-diagnosis as a predictor of changes in distress over the next 6 months and once with control at 9 months post-diagnosis as a predictor of changes in distress over the next 6 months. These longitudinal relationships were examined in patients only. In patients, distress was expected to be highest shortly after diagnosis and to decrease over time as a result of psychological adjustment. Such changes were not expected in the reference group. When a high level of personal control is related to a decrease in distress, the stress-buffer hypothesis is supported.

5.3 Results

Patients treated with CT were younger, reported less additional diseases than the other two groups and were more highly educated than patients not treated with CT (Table 5.1). The three groups were not significantly different with respect to the number of diseases for which one consulted a medical specialist. At 9 months post-diagnosis (T2), all patients completed treatment, with the exception of hormone therapy. A GLM repeated measures analysis showed that, controlling for age differences, the course of distress in patients was different from that in healthy women, $F_{\text{time x group}}(4,266) = 6.23$, $p <.01$. Patients reported most distress 3 months post-diagnosis (T1). In patients not treated with CT, distress decreased in the subsequent six months (T2). In patients treated with CT, the level of distress was no longer different from that in healthy women at 15 months post-diagnosis (T3).

Aim 1

Results show that, when controlling for group differences in educational level, in neither of the groups personal control changed significantly over time, $F_{\text{time}}(2,256) = 1.08$, $p = .34$ and $F_{\text{time x group}}(4,256) = 1.65$, $p = .16$. Yet, the overall mean level of personal control post-diagnosis did differ across groups, $F_{\text{group}}(2,128)$

Table 5.1 *Sample characteristics, means and standard deviations of personal control and distress*

	Healthy women	Patients non-CT	Patients CT
Age M (SD)[a]	52.8 (10.1)	54.9 (9.1)	48.3 (7.6)
Educational level n (%)[a]			
Elementary/lower professional	23 (40%)	26 (55%)	8 (25%)
Intermediate level professional	13 (22%)	10 (21%)	14 (44%)
Higher professional/academic	22 (38%)	11 (23%)	10 (31%)
Diseases not treated by specialist n (%)[b]			
0	19 (33%)	20 (43%)	23 (72%)
1	22 (38%)	10 (21%)	6 (19%)
2>	17 (29%)	17 (36%)	3 (9%)
Diseases treated by specialist n (%)[c]			
0	38 (66%)	27 (57%)	21 (66%)
1	13 (22%)	13 (28%)	8 (25%)
2>	7 (12%)	7 (15%)	3 (9%)
Treatment modalities			
Breast surgery		47 (100%)	32 (100%)
Radiotherapy		33 (70%)	10 (31%)
Hormone		19 (40%)	12 (38%)
Personal control M(SD)[d]			
3 months (T1)	24.6 (4.0)	24.4 (4.7)	24.4 (4.6)
9 months (T2)	25.4 (3.7)	25.0 (4.1)	23.2 (3.9)
15 months (T3)	25.5 (3.7)	25.1 (5.1)	24.1 (3.9)
Distress M(SD)[d]			
3 months (T1)	4.1 (2.1)	5.2 (3.2)	6.9 (3.0)
9 months (T2)	3.5 (3.5)	3.7 (3.7)	5.3 (3.3)
15 months (T3)	3.9 (2.9)	3.0 (3.0)	4.0 (3.3)
Total n	58	47	32

[a] Groups differ significantly, p<.05; [b] Groups differ significantly, p<.01; [c] Groups do not differ significantly; [d] Test results are reported in the text

Table 5.2 *Standardized regression coefficients (step 3), unstandardized coefficients (step 4) and percentages of explained variance per step*

		Distress								
		3 months			9 months			15 months		
		β (step 3)	B (step 4)	ΔR^2	β (step 3)	B (step 4)	ΔR^2	β (step 3)	B (step 4)	ΔR^2
	Cross-sectional[a]									
1	Age	-.23**	-0.08**	.06**	-.11	-0.03	.03*	-.19*	-0.06*	.04*
2	Patient non-CT	.18*	1.21*	.09**	.02	0.15	.04*	-.13	-0.80	.01
	Patient CT	.32**	2.44**		.13	0.49		-.07	-0.55	
3	Personal control	-.23**	-0.28**	.05**	-.43**	-0.25	.18**	-.32**	-0.16	.10**
4	Interaction patient non-CT[b]		0.22	.02		0.02			-0.08	
	Interaction patient CT		0.09			-0.35*	.04*		-0.12	.00
	Longitudinal (patients non-CT)[a]									
1	Initial level of distress (T1/T2)				.51		.31**	.57		.35**
2	Age				-.10		.05	-.05		.00
3	Personal control				-.20		.04	-.03		.00
	Longitudinal (patients CT)[a]									
1	Initial level of distress (T1/T2)				.57		.43**	.92**		.59**
2	Age				-.03		.00	-.19		.03
3	Personal control				-.31*		.09*	.21		.02

*$p < .05$; ** $p < .01$; [a] Controlled for group differences in age, related to distress; [b] Interaction between dummy and personal control

= 3.68, p = .03. Patients treated with CT reported less personal control after diagnosis than the reference group of healthy women, ΔEM= 1.67, SE = .74, $\underline{p}$ = .03. Univariate analyses show that this difference in personal control is largest at nine months after diagnosis ($\underline{ES}_{T1}$= .04, $\underline{ES}_{T2}$= .60, $\underline{ES}_{T3}$ = .37). The general level of personal control in patients not treated with CT did not differ from that in healthy women.

Aim 2

Results presented in Table 5.2 indicate that the diagnosis of breast cancer explained a significant percentage of variance in distress at T1 and T2, but not in distress at T3. The percentage of explained variance added by personal control was significant at all 3 occasions. Only at 9 months post-diagnosis (T2), a significant interaction effect was found. At that time, the control-distress relationship was significantly stronger in patients treated with CT than in healthy women. Longitudinal analyses showed that only in patients treated with CT a higher level of control at T1 was significantly related to declines in distress over the next six months. Control at T2 was significantly related to changes in distress over a period of six months (T3) in neither of the two patient groups.

5.4 Discussion

Results indicate that only patients treated with chemotherapy, who face a longer treatment trajectory and relatively less good prognostic prospects, report lower levels of personal control than healthy women (*Aim 1*). Although personal control was shown to be related to lower levels of distress, the results provide only modest support for the stress-buffering potential of control (*Aim 2*). Longitudinally, personal control 3 months post-diagnosis predicted a decrease in distress only in patients treated with chemotherapy. Cross-sectionally, women treated with chemotherapy were shown to profit more from a high sense of control over life than healthy women at 9 months after diagnosis. Interestingly, it is also in this phase of the illness trajectory, just after the completion of treatment, that the maintenance of sense of control seems hardest in this group. Patients are no longer monitored strictly and are assumed to get back to life as usual, without cancer playing a major role. There is finally time to reflect on the cancer experience and to face the risk of recurrence (Stanton et al., 2005; Ward, Viergutz, Tormey, DeMuth, & Paulen, 1992). Apparently, personal control is a valuable but threatened personal resource in this particular phase.

Patients who were not treated with chemotherapy resembled healthy women with respect to the reported levels of personal control and distress (with the exception of 3 months post-diagnosis). This study indicates that it is not the breast cancer diagnosis, but the required treatment modality and perhaps the related prognostic prospects that define the stress experience (Hoskins, Budin, & Maislin, 1996). Although some researchers suggest that objective clinical characteristics do no affect psychosocial outcomes in cancer patients (Bardwell et al., 2006), the current findings show that it is inadvisable to simply ignore differences.

The study has several limitations. First of all, the response rate was low and the two patient groups were rather small, consisted exclusively of women with an intimate partner, and may have existed from the least distressed women, as drop-outs and non-completers generally reported more distress and less personal control. Despite the limitations such a sample obviously has, such as limited external validity, one could argue that when significant relationships are found between variables that are restricted in range, results are even more robust. Moreover, the results were not depending on a few influential cases with more extreme scores.

Second, the study leaves questions about *why* personal control is adaptive and *how* personal control is maintained unanswered. Future studies should explore the possible behavioral and cognitive mediators of the control-distress relationship, including engagement in treatment decisions or self-efficacy for coping with cancer. Furthermore, researchers should try to gain more insight in the strategies people use to maintain personal control over life in the face of stressors like cancer. Possibly, patients who maintain control are those who are able to focus attention away from uncontrollable illness aspects and towards aspects that are still subject to personal control (Thompson, 2001; Baltes & Baltes, 1986), such as collecting information or reducing the impact of the illness on daily living. Moreover, by simply increasing the valence of life domains that are still controllable, like intimate relationships or spirituality, women might maintain a general sense of control over life. Insight in these underlying mechanisms, can provide clinical practice with valuable data to design interventions aimed at perceptions of control in cancer patients. Distress after a cancer diagnosis might be relieved by helping patients to reappraise or let go of temporarily unattainable goals and to identify the areas that are still subject to personal control.

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Chapter 6

The adaptive effect of personal control when facing breast cancer: cognitive and behavioral mediators

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Summary

Objective. This prospective study examines the cognitive and behavioral mediators of the relation between personal control and the initial response to a breast cancer diagnosis as well as subsequent psychological adjustment.

Methods. 143 patients participated immediately after diagnosis (T1), after surgery (T2) and 2 months after the end of treatment (T3), of whom 92 also completed a questionnaire pre-diagnosis (T0).

Results. The buffering effect of personal control on psychological distress shortly after diagnosis was mediated by cancer-specific cognitions, i.e., threat appraisal and coping self-efficacy. Moreover, a strong sense of personal control predicted lower levels of anxiety 2 months after the end of treatment, but was unrelated to distress at T3. The adaptive effect on anxiety was mediated by threat appraisal and active engagement in social life after surgery, but not by active patient participation or coping self-efficacy.

Conclusions. These results confirm and explain the adaptive effect of personal control. Apparently, women with a low sense of control appraise cancer and their personal coping skills more negatively, which makes them vulnerable to distress in response to diagnosis. Furthermore, women with a strong sense of control might regulate anxiety by remaining engaged in social life.

Numbering of assessments in this chapter compared to numbering in original design (Figure 1.1.)

Chapter 6	T0	T1-T2	T3
Original design	T1	T2-T3	T5

6.1 Introduction

Personal control refers to 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. A strong sense of personal control promotes psychological well-being and protects people against distress under various stressful circumstances (Compas, 1987; Folkman, 1984; Lefcourt & Davidson-Katz, 1991; Skinner, 1995). Even in people confronted with cancer, a disease characterized by considerable levels of uncertainty and uncontrollability, a high sense of personal control over life is related to more favorable outcomes (Bremer et al., 1997; Ell et al., 1989b; Ell et al., 1989a; Helgeson et al., 2004; Henselmans et al., 2009; Penninx et al., 1998). The current prospective study aims to explain the adaptive effect of personal control in women who are diagnosed with breast cancer.

Although numerous studies have demonstrated the adaptive effect of personal control in people facing stress, the mechanisms that lead from control to psychological well-being are less well known (Skinner, 1995). 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 et al., 2007). Knowledge about mediators might not only add to our theoretical understanding of the adaptive value of personal control, but might have practical significance for the development of interventions for distressed patients as well; i.e., while personal control over life in general might be hard to intervene upon, situation specific mediators might be more easy to change (Taylor & Stanton, 2007). Even though few studies explicitly examined mediators of the relation between control and well-being under stress, literature does suggest several cognitive as well as behavioral mechanisms.

Stress coping theory posits that the experience of stress depends on two different but related cognitive appraisal processes (Lazarus & Folkman, 1984), the individual's judgment of what is at stake (primary appraisal) and of the available coping resources (secondary appraisal). These appraisal processes are thought to be influenced not only by external factors (Paterson & Neufeld, 1987), such as the objective controllability of the situation, but also by personal beliefs and commitments, such as a general sense of control over life (Folkman, 1984). Research has demonstrated that individuals with a strong sense of control over life are less likely to appraise events as threatening or negative and generally perceive more coping opportunities (Jerusalem, 1993; Rodin et al., 1989; Taylor & Armor, 1996). This way, a strong sense of control might prevent the experience of chaos in stressful circumstances and might ensure that all cognitive resources remain available (Skinner, 1995). Several studies have linked both primary appraisal and secondary appraisal to successful adjustment in cancer patients (Hamama-Raz et al., 2007; Manne et al., 2006; Merluzzi et al., 2001; Vinokur et al., 1990). For example, in a recent study among 300 melanoma survivors, Hamama-Raz et al. (2007) demonstrated that low threat appraisal and high appraisal of coping abilities promoted well-being and lowered distress. Such appraisal processes turned out to be more important than objective medical factors like stage of the illness. Nevertheless, to our knowledge, no study has investigated whether and to what extent the beneficial effect of personal control is mediated by such cancer-specific appraisal processes.

Besides cognitive appraisal processes, also differences in behavior might explain the beneficial effect of personal control. Several researchers have suggested that a strong sense of control fosters approach-oriented, (pro-)active and task-centered coping, as well as problem solving, persistence, information seeking and the maintenance of action under stressful conditions (Anderson, 1977; Aspinwall & Taylor, 1997; Folkman, 1984; Lefcourt & Davidson-Katz, 1991; Skinner, 1995; Strickland, 1978). Such active, approach-oriented coping strategies are generally found to be more adaptive than avoidant, passive and disengaging strategies (Felton & Revenson, 1984; Hack & Degner, 2004; Taylor & Stanton, 2007). Active behavior might prevent feelings of helplessness, limit the negative consequences of the stressor and prevent secondary stress on other life domains.

The current study tests the mediating effect of two types of active behavior in women diagnosed with breast cancer. First, personal control might promote patients' active participation in medical interactions. Active patient participation, i.e., asking questions, contributing to the conversation and being involved in decisions has been shown to reduce anxiety, to promote patient satisfaction and to encourage physicians to provide more support and information (Kaplan et al., 1989; Stewart, 1995; Street et al., 2005). The second type of active behavior that might play a mediating role is patients' active participation in social life, i.e., the extent to which the patient is not avoiding or neglecting contacts with friends and acquaintances outside the close family. Even though cancer can have a large negative impact on patients' social life, especially during treatment, a strong sense of personal control over life might prevent disengagement from the social domain. Actively participating in social life might in turn promote psychological well-being in multiple ways. First of all, social activities might provide distraction and draw attention away from having cancer. Patients often stress the importance of maintaining normal daily activities (Luoma & Hakamies-Blomqvist, 2004). Similarly, participating in social life might compensate for losses on certain other areas of life, for example physical activity or work. Lastly, remaining in contact with people outside the close circle enhances social support provision, which might help to reduce anxiety (e.g., Hipkins et al., 2004).

In sum, literature suggests that a strong sense of control over life promotes beneficial cognitive appraisal as well as active engagement in the face of an adverse event like a cancer diagnosis. The present study examined if these factors explain the effect of personal control on the *initial response* to the diagnosis as well as the effect of control on the subsequent psychological *adjustment*. Women with a strong sense of control before diagnosis might report a smaller increase in distress *right after diagnosis*, as they appraise less threat and have more confidence in their personal coping skills than women with a low sense of control. In this immediate response to diagnosis, individual differences in active behavior are assumed not to play a mediating role. In addition, women with a strong sense of control over life after diagnosis might be better able to normalize their initially elevated levels of distress in the period from *diagnosis* until *the end of treatment*, because they appraise having cancer less negatively and because they are more engaged in medical interactions and in social life during the period of *active treatment* than women with a low sense of control.

In short, we hypothesized that (1a) personal control before a breast cancer diagnosis is related to less psychological distress immediately after diagnosis and (1b) that this relation is mediated by both primary and secondary cognitive appraisal. In addition, we hypothesized that (2a) personal control after diagnosis is related to less psychological distress and anxiety two months after the end of treatment and (2b) that this relation is mediated by the two appraisal processes as well as by the two types of active engagement in the period of active treatment.

6.2 Method

Sample

Six hospitals in the Northern part of the Netherlands were involved in the recruitment of respondents. The study protocol was approved by the Medical Ethical Committees. Women who were referred to the hospital because of a suspicion of breast cancer (based on self-examination, GP's examination or screening) were invited to participate by mail. Women were eligible if they (1) were 75 years old or younger, (2) did not have a serious psychiatric disorder or a somatic disorder that implied hospital admission, (3) comprehended Dutch, (4) followed the usual diagnostic protocol and (5) did not have a history of cancer. The present paper reports on the data of women who were diagnosed with a malignant breast tumor and who were treated with curative intent. The timing of assessments was linked to meaningful events, i.e., diagnosis, surgery, adjuvant treatment and end of treatment (Heim et al., 1997). To avoid differences in the order of these events, 10 patients treated with neo-adjuvant chemotherapy were excluded from the study.

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 whom 1226 gave informed consent prior to diagnosis (40%), of whom 1094 met the inclusion criteria. Of these 1094 women, 912 women could be contacted within 6 weeks after diagnosis and were willing to confirm their pre-diagnosis consent. Of these 912 women, 242 women were diagnosed with breast cancer. This paper reports on four assessments: before first clinic visit for diagnostic testing (T0; on average one week before diagnosis), shortly after diagnosis but before surgery (T1; on average 12 days after diagnosis), right after surgery and before or just after the start of adjuvant treatment (T2; on average 2 months after diagnosis) and two months after the end of complete treatment (T3; on average 7 months after diagnosis).

Due to the short time span between referral and the first clinic visit, as well as between diagnosis and first surgery, not all patients could participate at T0 and T1. Often there was simply not enough time to post and fill out the questionnaire. A total of 143 patients completed the necessary questionnaires at T1, T2 and T3. Of these 143 patients, 92 had also completed the pre-diagnosis questionnaire (T0). The data of this subsample were used to test the hypotheses regarding the initial response; the data of the larger sample were used to test the hypotheses regarding subsequent adjustment. This way, we maximized power and made optimal use of all available data. As two rather distinct research questions were addressed, we saw no reason to limit our analyses to women with a pre-diagnosis assessment only when testing the second hypothesis. Neither the 143 patients who completed T1-T3, nor the subsample of 92 women who also completed T0, differed from the patients not included in the analyses with respect to age, medical characteristics or the psychological concepts included in the current study.

Instruments

Personal control over life was assessed with the 7-item Mastery List (Pearlin & Schooler, 1978) reflecting the perceived personal control over events and situations in life. An example item is: ‘Sometimes I feel that I am being pushed around in life’. The five response categories ranged from ‘completely agree’ to ‘completely disagree’. Alphas were .84 (T0) and .83 (T1).

Primary threat appraisal was assessed with ten items based on a item set of Vinokur (Vinokur et al., 1990), asking about worries over the impact breast cancer has or will have on ten important life domains (e.g., daily activities, romantic life, appearance, relationship with family, relationship with friends, future prospects, emotions, recreational activities, financial situation, independence). The four response categories ranged from ‘no worries’ to ‘many worries’. Alphas were .90 (T1) and .88 (T2).

Secondary appraisal was assessed with the Cancer Behavior Inventory (Merluzzi et al., 2001), reflecting self-efficacy for coping with cancer. Patients were asked to indicate how confident they were that they could accomplish 14 different cancer-specific behaviors, e.g., remaining a sense of humor, sharing concerns, dealing with physical changes etc. The ten response categories ranged from ‘not at all confident’ to ‘totally confident’. The original English version was translated by a professional translator. The resulting Dutch version was checked on fluency and comprehensibility by independent Dutch-speaking persons. Alphas were .89 (T1) and .85 (T2).

Patient participation was assessed with four selected items of the information subscale of the Krantz Health Opinion Survey (Krantz et al., 1980). Although this subscale with originally seven items was constructed to assess patients’ information preference, Nease et al. (1995) concluded that four out of seven items are more a reflection of what the patient usually does than of the patient's preference (e.g., "Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health" and "I usually ask the doctor or nurse lots of questions about the procedures during a medical exam"). We included only these four items to assess active patient behavior. The five response categories ranged from 'completely agree' to 'completely disagree'. The alpha of the four items was .70 (T2).

Engagement in social life was assessed with a self-constructed item set of eight items based on the subscale social activities of the Sickness Impact Profile (Bergner et al., 1981) and on the Groningen Social Behavior Questionnaire (De Jong & Van der Lubbe, 2001). All items needed to be reverse coded as they reflected disengagement from social life. Examples of items are 'Lately I contacted my friends or acquaintances less than usual', 'Lately I avoided contacts outside my close family' or 'Lately I preferred not going to parties'. The five response categories ranged from 'completely agree' to 'completely disagree'. The alpha was .89 (T2).

Psychological distress was assessed with the 12-item version of the General Health Questionnaire (Goldberg & Williams, 1988). Respondents were asked to compare their present state with their usual state with respect to, e.g., problems with sleeping, enjoyment of daily activities, general happiness, etc. The total scale score was calculated by counting the number of items on which the respondent indicated a state that was 'worse' or 'much worse' than usual. This results in a score range of 0-12. Alphas were .87 (T0) and .86 (T1) and .91 (T3). Distress was the only psychological outcome that was assessed before diagnosis (T0).

Anxiety was assessed with the short 6-item version of the state scale of the Spielberg State and Trait Anxiety Inventory (Marteau & Bekker, 1992; Spielberger & Gorsuch, 1970). Respondents were asked to rate the degree to which they were currently experiencing each anxiety symptom on a 4 point scale ranging from 'not at all' to 'very much so'. Alphas were .86 (T1) and .88 (T3).

Analysis

Descriptive bivariate associations were examined by means of Pearson correlations or ANOVAs. Changes in anxiety and distress over time were tested by means of paired t-tests. Mediation was examined by means of regression analyses. To examine the effect of personal control on the *initial response* to diagnosis, distress at T1 was included as the dependent variable. Distress at T0 (step 1), personal control at T0 (step 2) and the cognitive mediators at T1 (step 3) were entered as predictors. As anxiety was not assessed at T0, we could only examine the initial response in distress. To examine the effect of personal control on the *subsequent adjustment* to diagnosis, both distress at T3 and anxiety at T3 were included as the dependent variables in separate analyses. Distress at T1 (step 1), personal control at T1 (step 2) and the cognitive mediators at T2 (step 3) were entered as predictors.

In both models we first tested the mediation effect of each mediator separately, by examining the difference between the total effect of personal control on the outcome (c) and the effect of personal control on the outcome once the mediator was included (c′). This indirect effect (c - c′) was tested for statistical significance by computing 95% confidence intervals through bootstrapping (Preacher & Hayes, 2008). Bootstrapping means drawing multiple samples from the dataset (5000 in the current study) and estimating the effect in each of these samples to get an approximation of the sampling distribution. These indirect effects are then ordered and the middle 95% (100(1- α)%) of these estimations are used to define the confidence interval. When zero is not included in this interval, the indirect effect is considered significantly different from 0. In case of multiple significant single mediators, a multiple mediator model was examined to determine the mediating effect of the total set of mediators as well as the unique contribution of each mediator. The contribution of each mediator in the multiple mediator model was calculated by multiplying the effect of personal control on the mediator (a) and the effect of the mediator on the outcome (b). The sum of these unique contributions equals to the total indirect effect ($\Sigma ab = c - c'$). Lastly, we tested the contrast between the unique contributions of multiple mediators, to determine if the contributions differ significantly from each other. For all analyses we made use of a macro provided by Preacher and Hayes (2008). R^2 will be presented to indicate effect size. The unstandardized coefficients were used to calculate the indirect effects and confidence intervals, yet to enable interpretation the standardized coefficients will be reported as well.

6.3 Results

Descriptives

Patients' demographic and medical characteristics are presented in Table 6.1 for the total sample (n = 143) and the subsample (n = 92). The subsample was rather similar to the total sample and both resembled the regional population of women diagnosed with breast cancer in 2005 (Comprehensive Cancer Center North-Netherlands Cancer Registry; n = 1506, age <= 75, at least surgical treatment) with respect to age (M = 57, SD = 11) and cancer stage (stage 0 11%, stage 1 39%, stage 2 36%, stage 3 12%, stage 4 1%).

Table 6.2 shows the means and standard deviations for personal control, the cognitive and behavioral mediators and the psychological outcome measures. Only the assessments included in the hypothesized mediation models were presented. Paired t-tests showed that distress significantly increased after diagnosis and that both distress and anxiety significantly decreased two months after the end of treatment. Primary threat appraisal after diagnosis (T1) and after surgery (T2) was rather low. A mean score of 15 indicates that women did not have many concerns regarding the impact of breast cancer on their lives. Specifically, women were most concerned about the impact breast cancer has or will have

Table 6.1 *Sample characteristics of the total sample and of the subsample that completed a pre-diagnosis questionnaire*

		Total sample	Subsample
Age M (SD; range)		55.7 (9.5; 31-75)	56.5 (9.3; 36-75)
Children under 18 (%)		34 (24%)	20 (22%)
Educational level n (%)			
	Elementary/low-level professional	52 (36%)	39 (42%)
	Intermediate-level professional	51 (36%)	30 (33%)
	High-level professional/ academic	40 (28%)	23 (25%)
Cancer stage n (%)			
	0	10 (7%)	8 (9%)
	1	54 (38%)	39 (43%)
	2	62 (43%)	36 (39%)
	3	17 (12%)	9 (10%)
Treatment n (%)			
	Surgery only	21 (15%)	16 (17%)
	Radiotherapy (RT)	55 (39%)	38 (41%)
	Chemotherapy (CT)	19 (13%)	15 (16%)
	Both RT and CT	48 (34%)	23 (25%)
N		143	92

on their daily activities, their future perspective and their emotions; and least concerned about the impact on relationships and their financial situation. On average, women were also confident in their ability to cope with the stressors cancer brings at T1 and T2. Similarly, engagement in social life was rather high at T2 ($M = 32$). Most women remained in contact with friends and did not neglect social contacts during treatment, although 30% of the women did indicate that they did not make as many visits as usual and preferred not to go to parties lately. Lastly, patients' scores on active patient participation at T2 are positioned in the middle of the 4 item scale.

Testing for confounders

The possible confounding effect of the demographic and medical characteristics (Table 6.1) was tested by examining the bivariate associations with personal control and the psychological outcome measures in both samples. Higher age was significantly related to lower levels of personal control pre-diagnosis, $r = -.22$, $p = .03$, n = 92. Furthermore, women with a low educational level reported

Table 6.2 *Means and standard deviations of personal control, mediators and outcomes*

	Before diagnosis (T0)	After diagnosis (T1)	After surgery (T2)	After end treatment (T3)
Initial response model (n=92)				
Personal control (range 7-35)	24.8 (5.1)			
Threat appraisal (10-40)		15.9 (5.0)		
Coping self-efficacy (14-126)		97.7 (16.3)		
Distress (range 0-12)	2.2 (2.9)	3.4 (3.3)[a]		
Subsequent adjustment model (n=143)				
Personal control (range 7-35)		25.2 (5.2)		
Threat appraisal (range 10-40)			14.8 (4.5)	
Coping self-efficacy (range 14-126)			97.8 (14.2)	
Engagement in social life (range 8-40)			31.7 (6.2)	
Patient participation (range 4-20)			13.1 (2.9)	
Distress (range 0-12)		3.4 (3.2)		2.4 (3.4)[b]
Anxiety (range 6-24)		13.3 (3.8)		10.5 (3.5)[c]

[a] Significant increase in distress, t(91) = -4.76, p<.001; [b] Significant decrease in distress, t(142) = 3.41, p<.01; [c] Significant decrease in anxiety, t(142) = 10.16, p<.001.

less personal control pre-diagnosis than women with intermediate or high-level education, $F(2,89) = 7.404$, $p < .01$, n = 92. Lastly, patients prescribed with adjuvant chemotherapy only reported the most distress right after diagnosis, $F(3,88) = 2.858$, $p = .04$, n = 92. Yet, a regression analysis including these variables in the first step showed that these characteristics did not limit the predictive effect of personal control on distress after diagnosis. For this reason, none of the characteristics was included in the mediation models.

Table 6.3 *Pearson correlations between the variables included in initial response mediation model (n = 92)*

		1	2	3	4	5
1	Personal control T0	1				
2	Threat appraisal T1	- .50†	1			
3	Self-efficacy T1	.61†	- .60†	1		
4	Distress T0	- .43†	.39†	- .38†	1	
5	Distress T1	- .47†	.55†	- .55†	.69†	1

T0 before diagnosis; T1 right after diagnosis, T2 after surgery, T3 two months after the end of treatment
† p<.01

Correlations

Table 6.3 and Table 6.4 show the Pearson correlations between the variables included in respectively the short-term (n = 92) and the long term (n = 143) mediation models. Personal control over life was negatively related to both distress and anxiety. Furthermore, personal control was negatively related to

Table 6.4 *Pearson correlations between the variables included in the subsequent adjustment mediation model (n = 143)*

		1	2	3	4	5	6	7	8	9
1	Personal control T1	1								
2	Threat appraisal T2	- .33†	1							
3	Self-efficacy T2	.46†	- .56†	1						
4	Patient behavior T2	.08	.13	.13	1					
5	Social engagement T2	.42†	- .35†	.41†	.03	1				
6	Distress T1	- .54†	.41†	- .46†	.03	- .40†	1			
7	Distress T3	- .27†	.44†	- .29†	.05	- .29†	.47†	1		
8	Anxiety T1	- .53†	.41†	- .43†	.03	- .28†	.67†	.44†	1	
9	Anxiety T3	- .45†	.40†	- .38†	- .08	- .34†	.53†	.70†	.60†	1

T1 right after diagnosis, T2 after surgery, T3 two months after the end of treatment

† p<.01

Table 6.5 *Regression results of the initial response as well as the subsequent adjustment mediation models*

	Step 1			Step 2			Step 3			95% CI unstandardized coefficients indirect effects		
	B	β	ΔR^2	B	β	ΔR^2	B	β	ΔR^2	Total ^{a}	Unique ^{b}	Contrast ^{c}
Initial response												
Distress T1												
Distress T0	.80†	.69†	.48†	.69†	.60†	.04*	.62†	.54†	.07†	-.08 (-.17 to -.03)		
Control T0				-.14*	-.21*		-.05	-.08				
Appraisal T1							.20†	.31†				
Distress T0	.80†	.69†	.48†	.69†	.60†	.04*	.64†	.56†	.06†	-.11 (-.18 to -.06)		
Control T0				-.14*	-.21*		-.02	-.04				
Efficacy T1							-.06†	-.31†				
Distress T0	.80†	.69†	.48†	.69†	.60†	.04*	.60†	.52†	.09†	-.14 (-.22 to -.07)		
Control T0				-.14*	-.21*		.00	.00				
Appraisal T1							.15*	.23*			-.06 (-.14 to -.01)	.01 (-.09 to .10)
Efficacy T1							-.04*	-.21*			-.08 (-.14 to -.02)	
Adjustment												
Distress T3												
Distress T1	.50†	.47†	.22†	.48†	.45†	.00						
Control T1				-.02	-.03							

T0 before diagnosis; T1 right after diagnosis, T2 after surgery, T3 two months after the end of treatment; * $p<.05$, † $p<.01$; a total indirect effect, i.e., c (total effect control) – c'(direct effect control); b contribution of each mediator in the multiple mediator model, i.e., a (effect of control on mediator) x b (effect of mediator on outcome); c The difference between the unique contributions of the mediators included in the multiple mediator model.

Table 6.5 *Continued*

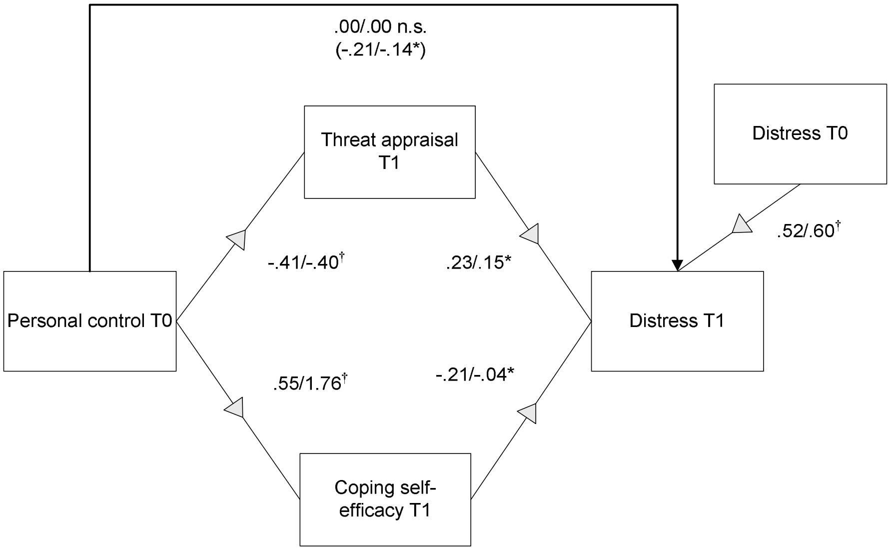
	Step 1			Step 2			Step 3			95% CI unstandardized coefficients indirect effects		
	B	β	ΔR^2	B	β	ΔR^2	B	β	ΔR^2	Total^a	Unique^b	Contrast^c
Anxiety T3												
Anxiety T1	.55†	.60†	.36†	.46†	.51†	.02*	.41†	.46†	.02*	-.02 (-.06 to -.001)		
Control T1				-.12*	-.18*		-.10	-.15				
Appraisal T2							.12*	.16*				
Anxiety T1	.55†	.60†	.36†	.46†	.51†	.02*	.44†	.48†	.01	-.02 (-.07 to .01)		
Control T1				-.12*	-.18*		-.10	-.15				
Efficacy T2							-.03	-.11				
Anxiety T1	.55†	.60†	.36†	.46†	.51†	.02*	.45†	.50†	.02*	-.04 (-.09 to -.003)		
Control T1				-.12*	-.18*		-.08	-.13				
Engagement T2							-.08*	-.15*				
Anxiety T1	.55†	.60†	.36†	.46†	.51†	.02*	.42†	.46†	.03*	-.04 (-.11 to -.01)		
Control T1				-.12*	-.18*		-.08	-.11				
Appraisal T2							.10	.13			-.01 (-.05 to .001)	-.01 (-.03 to .06)
Engagement T2							-.06	-.11			-.03 (-.08 to .01)	

T0 before diagnosis; T1 right after diagnosis, T2 after surgery, T3 two months after the end of treatment; * $p<.05$, † $p<.01$
a total indirect effect, i.e., c (total effect control) – c′(direct effect control); b contribution of each mediator in the multiple mediator model, i.e., a (effect of control on mediator) x b (effect of mediator on outcome); c The difference between the unique contributions of the mediators included in the multiple mediator model.

threat appraisal, whereas positively to coping self-efficacy and engagement in social life. Both strong coping-self-efficacy as well as high engagement in social life were related to less distress and anxiety, whereas high threat appraisal was related to less favorable outcomes. Active patient participation was not related to any of the variables included in the models and was therefore not tested as a potential mediator.

Mediation: initial response to diagnosis
Regression analysis showed that distress before diagnosis (T0) was a strong predictor of distress after diagnosis (T1; Table 6.5). Furthermore, personal control over life at T0 was negatively related to psychological distress at T1. A closer examination of this relation showed that the 33 women who were not distressed before nor after diagnosis (cut-off >= 2, Goldberg & Williams, 1988; Koeter & Ormel, 1991) scored 4 points higher on personal control pre-diagnosis than the 22 women who were not distressed before but became distressed after diagnosis (effect size = 0.8) and almost 5 points higher than the 35 women who were distressed right before as well as after diagnosis (effect size = 1.0).

Figure 6.1 *Final mediation model for psychological distress right after diagnosis*



T0 before diagnosis; T1 right after diagnosis.
Standardized coefficient β /unstandardized coefficient B; the estimates between brackets represent the total effect of personal control (c; direct plus indirect); * p<.05, † p<.01

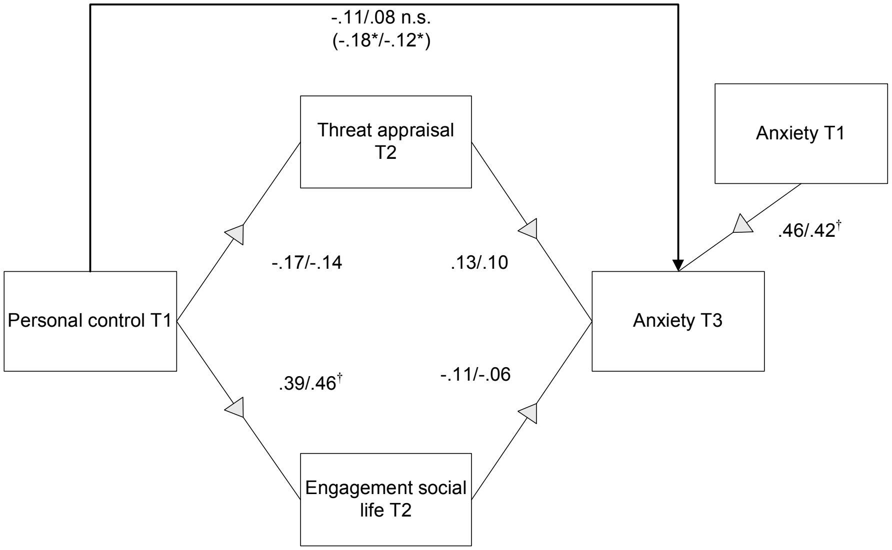
Single mediator models showed that both threat appraisal and coping self-efficacy mediated the adaptive effect of personal control, i.e., the inclusion of both types of appraisal significantly reduced the total effect of personal control on distress after diagnosis. The multiple mediator model (Figure 6.1) showed that both threat appraisal and coping self-efficacy independently contributed to the indirect effect of personal control and that there was no significant difference between the contributions of the two mediators.

Mediation: subsequent psychological adjustment
Regression analysis showed that distress right after diagnosis (T1) was a strong predictor of distress after the end of treatment (T3; Table 6.5). Personal control at T1 was however not significantly related to distress at T3 and mediation was not examined.

Anxiety right after diagnosis was a strong predictor of anxiety after the end of treatment. Furthermore, personal control at T1 could explain a significant percentage of variance of anxiety at T3. A closer examination of this relation showed that the 40 women who had rather high scores on anxiety at T1 right after diagnosis (scores > 13, indicating a respondent is more than 'a little' anxious) but recovered at T3 after the end of treatment, scored 2.5 points higher on personal control than the 22 women who were anxious at both occasions (effect size = 0.5).

Single mediator models showed that both threat appraisal and engagement in social life at T2 were significant mediators of the relation between control at T1 and anxiety at T3. However, both mediating effects were only just significant and rather small, i.e., the reductions in the effect of personal control were marginal

Figure 6.2 *Final mediation model for anxiety after the end of treatment*



T1 right after diagnosis, T2 right after surgery, T3 two months after the end of complete treatment. Standardized coefficient β /unstandardized coefficient B; the estimates between brackets represent the total effect of personal control (c; direct plus indirect); * p<.05, † p<.01

compared to the indirect effects in the model of the initial response to diagnosis. When both mediators were entered simultaneously in a multiple mediator model (Figure 6.2), the total indirect effect was significant, yet the unique contributions of the two mediators were not, indicating overlap between the two.

6.4 Discussion

In line with the first set of hypotheses, the current study demonstrates that a strong sense of personal control over life before diagnosis protects women from distress immediately after a breast cancer diagnosis (*1a*). Cognitive appraisal seemed to be an important underlying mechanism, i.e., patients' primary appraisal of the impact of breast cancer on life and patients' secondary appraisal of personal coping skills fully mediated the adaptive effect of personal control (*1b*). The second set of hypotheses, addressing psychological adjustment after the initial response, was only partly supported. Personal control over life right after diagnosis predicted less anxiety two months after the end of treatment, but was unrelated to changes in psychological distress (*2a*). The adaptive effect of personal control on anxiety was significantly mediated by threat appraisal and active engagement in social life after surgery, while coping self-efficacy and active patient participation did not play a mediating role (*2b*).

To our knowledge, this is the first study to empirically demonstrate that cancer patients with a strong sense of control over life *pre-diagnosis* are less likely to experience an increase in psychological distress *post-diagnosis*. Examination of primary and secondary cognitive appraisal showed that, in line with theory (Folkman, 1984; Taylor & Armor, 1996), women with a strong sense of control appraised the cancer situation less negatively and were more confident in their abilities to cope effectively with the stressors cancer brings. The distinct relations between personal control and stress appraisal on the one hand (e.g., Jerusalem, 1993; Taylor & Armor, 1996) and between stress appraisal and psychological well-being on the other (e.g., Hamama-Raz et al., 2007; Manne et al., 2006) have been studied before. However, in addition to the existing literature, the current study combines both relations in one model and shows that appraisal processes actually mediate the adaptive effect of a general sense of control over life in cancer patients.

In contrast to the lack of studies addressing the relation between personal control and the first response to diagnosis, a number of studies have demonstrated the beneficial effect of personal control on psychological adjustment *after* the initial response (e.g., Helgeson et al., 2004; Henselmans et al., 2009; Penninx et al., 1998). Our results partly support these findings, i.e., personal control right after diagnosis was a predictor of anxiety two months after the end of treatment, yet not of psychological distress. In an earlier study, we did find a relation between personal control three months after diagnosis and psychological distress nine months after diagnosis, but only in women treated with chemotherapy (Henselmans et al., 2009). Additional analyses showed that in the current study, chemotherapy did not have this moderating effect. A possible explanation for the difference between the findings for distress and anxiety could lie in the design of the current study, wherein predictor and outcomes are assessed at meaningful moments in the illness trajectory instead of at certain points in time after diagnosis. Two months after the end of treatment, psychological distress might be affected by physical recovery to some extent, while anxiety might be defined more exclusively by personal characteristics, like perceived control over life. Nevertheless, we expected personal control to predict both outcomes and future research should look into the differences between these measures of psychological well-being more closely.

Active engagement in social life had a mediating role in the recovery in anxiety after diagnosis, even though the effect was small and overlapping with the similarly small mediating effect of threat appraisal. Apparently, women with a strong sense of personal control over life at the time of diagnosis remained more engaged in their social life in the active treatment phase, which made them better able to regulate initial anxiety. Actively participating in social life might help to reduce anxiety in multiple ways, i.e. by providing distraction, by compensating for losses on certain other areas of life or by enhancing social support provision. Future research should look into the function of engagement in social life more closely. Furthermore, if our findings are replicated, encouraging cancer patients to remain engaged in social life in the active treatment phase could become part of intervention programs.

Unexpectedly, personal control over life was not related to active patient participation in medical interactions over time, nor was active patient participation related to anxiety or distress. A closer examination revealed that, cross-sectionally, active patient participation right after surgery (T2) was weakly related to personal control, $r = .19$, p = .02, yet not to the psychological outcomes. To interpret these findings, we examined the linearity of the relations between active patient participation on the one hand and personal control and the psychological outcomes on the other hand by plotting these associations. Possibly, both very low as well as very high active participation reflect a lack of control and poor psychological outcomes. There was however no evidence for such a quadratic relation. A potential explanation for our findings could be the assessment of active participative behavior by using self-report instead of the observation of actual participative behavior during consultations. Patients' judgment of their own behavior during medical consultations, might differ from their actual behavior and might therefore be unrelated to psychological well-being. However, the rather weak relations with personal control remain difficult to interpret and it would be interesting if future research would examine the relation between general as well as disease-specific control perceptions and observable patient behavior during medical interactions in more detail.

The current study has several strengths. First of all, the inclusion of a pre-diagnosis assessment enabled the examination of the initial response to a breast cancer diagnosis. Furthermore, the study included several post-diagnosis assessments, i.e., after diagnosis, surgery and the end of complete treatment, which made it possible to examine adjustment over various meaningful stages in the illness trajectory. Lastly, the study sample is representative for the regional population of women with newly diagnosed breast cancer with respect to cancer stage, treatment variables and age.

However, several limitations should be addressed as well. First of all, related to the design of the study that included assessments right before diagnosis and surgery, not all patients had complete data. Yet, the finding that the patients who could not be included in the analyses were not different from the patients who were with respect to any of the variables described in this study increases our confidence that the results were not biased as a result of excluding incomplete cases. Second, the pre-diagnosis assessment does not constitute a true baseline assessment, as the suspicion of breast cancer was already raised. Pre-diagnosis distress scores indicate that patients were already mildly distressed at the time of diagnostic testing. Nevertheless, post-diagnosis distress scores were considerable higher, indicating a response to the definite bad news. Third, as our longitudinal study asked a lot of patients' cognitive resources at times, e.g., during two 1,5 hour interviews, very old patients, (>75) were excluded. As a consequence, the included sample is somewhat younger (M = 56) than the national population of newly diagnosed breast cancer patients (M = 60) and conclusions do not generalize to the very old. Lastly, even though our prospective design enabled some causal interpretation, it is still the researcher who implies causality when testing theoretical mediation models. For example, Carver et al. (2003) theorized and empirically demonstrated that dispositional pessimism in women with breast cancer (predictor) was related to emotional distress (mediator), which predicted disruption of social activities (outcome). In contrast, in our model distress was considered the outcome and engagement in social life the mediator. Even though theory has strongly guided us in formulating our hypotheses, we do recognize the possibility of reciprocal relations between some of the constructs in this study.

In conclusion, the current study offers more insight in the underlying mechanisms of the protective effect of personal control. These findings might direct the development of psychological interventions offered to patients, as targeting interventions on appraisal or on patients' engagement in social life might be more successful than intervening upon a lack of control over life in general (Arnold et al., 2006). For example, Giese-Davis et al. (2006) demonstrated that peer-counseling shortly after a breast cancer diagnosis improved women's self efficacy for coping with cancer. Furthermore, Antoni et al. (2006) showed that breast cancer patients reported less disruptions in social and interpersonal activities after a behavioral stress management intervention. Furthermore, the findings of the current study add to our theoretical understanding and direct further research on how a personal resource like perceived control over life can affect the initial response and the subsequent adjustment to the diagnosis of a serious illness like cancer.

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Chapter 7

Personal control over the cure of breast cancer: adaptiveness, underlying beliefs and correlates

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Summary

Objective. Whereas cognitive adaptation theory suggests that personal control acts as a stress buffer when facing adversity, maladaptive outcomes might occur when control is disconfirmed. The moderating effect of disappointing news on the adaptiveness of personal control over cure in women with breast cancer was examined and contrasted with the effect on the adaptiveness of general control over life. Additionally, the underlying beliefs and correlates of control over cure were explored.

Methods. Women with newly diagnosed breast cancer were assessed after surgery (n = 228). For a sub-sample (n = 133) data before surgery and after the end of treatment were available as well. Data were collected through questionnaires and face-to face interviews. The prescription of chemotherapy after surgery was used as an indicator of disappointing news.

Results. A chemotherapy prescription did not enhance nor limit the adaptiveness of disease-specific or general control perceptions. Women reported that maintaining a positive attitude, accepting treatment and adopting a healthy life style gave them a sense of control over cure. Women with a strong sense of control over cure more often had invasive cancer, were younger and were best characterized by high optimism and strong sense of control over life.

Conclusions. The findings add to our understanding of exaggerated control perceptions in cancer patients treated with curative intent and do not give reason to assume that such perceptions should be altered because of potentially maladaptive effects. On the contrary, a strong sense of control over the cure of breast cancer seems to reflect the capacity to adapt.

Numbering of assessments in this chapter compared to numbering in original design (Figure 1.1)

Chapter 7	T0-T1	T2
Original design	T2-T3	T5

7.1 Introduction

The chances of surviving cancer depend for a large part on the characteristics of the tumor and the effectiveness of treatment. Consequently, there is generally not much patients can do to personally affect cure. Seemingly contradictory, media accounts of cancer experiences often use language with connotations to warfare or sports (Clarke & Everest, 2006; Seale, 2001), like 'fighting' or 'defeating' cancer (Doan & Gray, 1992). Moreover, in various studies, cancer patients have reported having a considerable degree of personal control over disease progression, cure, and recurrence (Carver et al., 2000; Malcarne, Compas, Epping-Jordan, & Howell, 1995; Lowery, Jacobsen, & DuCette, 1993; Taylor, Lichtman, & Wood, 1984). Whether such exaggerated control beliefs are adaptive at all times, is still subject to debate (Lowery et al., 1993; Christensen, Turner, Smith, & Holman, 1991; Taylor et al., 1984). In the current study, we aim to examine the adaptiveness and meaning of a sense of control over the cure of breast cancer. The findings will add to our theoretical understanding of exaggerated control perceptions, as well as to our knowledge on how to handle these perceptions in clinical practice.

Adaptiveness of control over cure

Taylor's cognitive adaptation theory posits that people generally hold overly positive views about themselves, which enhance their well-being under normal as well as under stressful circumstances (Taylor & Brown, 1988; Taylor, 1983). Engaging in mildly positive self-relevant distortions enables people to maintain an optimistic outlook, self-esteem and a sense of mastery when facing a threatening event. The generation of a sense of personal control over objectively uncontrollable events is an example of such a distortion. Taylor argued that self-generated control perceptions prevent helplessness and promote constructive thought and action (Thompson, 1999). Supporting cognitive adaptation theory, several studies have demonstrated that patients with a strong sense of control over their disease were better adjusted than patients with weak control perceptions (Barez, Blasco, Fernandez-Castro, & Viladrich, 2007; Lowery et al., 1993; Taylor et al., 1984). Moreover, disease-specific control perceptions seem to be particularly adaptive when threat is high or when the disease is severe (Helgeson, 1992; Affleck, Tennen, Pfeiffer, & Fifield, 1987; Folkman, 1984).

However, several researchers have also demonstrated maladaptive outcomes of disease-specific control beliefs when these are not, or no longer, confirmed (Tomich & Helgeson, 2006; Folkman, 1984). For example, Christensen et al. (1991) reported that renal patients with a strong sense of control over health reported more depressive symptoms after a failed renal transplant than patients with a low sense of control. Similarly, Helgeson (1999) showed that disease-specific control was maladaptive in cardiac patients who experienced a new coronary event, while it was adaptive in patients who did not.

Whether or not a belief in control is maladaptive when confronted with a deterioration or a setback might depend on the specificity of the belief. Janoff-Bulman (1989) theorized that only very *specific*, lower order beliefs are vulnerable to disconfirmation, while more *general* beliefs do not necessarily have to be realistic to be adaptive, as they can draw from many different sources and are not easily disconfirmed. In support of this assumption, Helgeson and Fritz (1999) reported that a general sense of control was adaptive in cardiac patients who experienced a setback, while disease-specific control was not. Additionally, Tomich & Helgeson (2006) showed that general positive beliefs after a first breast cancer diagnosis promoted well-being after a recurrence, while a belief in illness-specific control did not.

Besides the study of Tomich and Helgeson (2006), no study has addressed the moderating effect of a deterioration or setback on the adaptiveness of disease-specific personal control in women with breast cancer. Two hypotheses can be formulated regarding the direction of this effect. First, based on cognitive adaptation theory, personal control might be a stress-buffering belief, i.e., personal control might gain in importance after a setback. Second, based on the assumption that the disconfirmation of control leads to maladaptive outcomes, personal control might turn out to be disadvantageous when confronted with a setback. A strong belief in personal control might prevent women from mentally preparing for a disappointment and might provoke feelings of inadequacy and responsibility (Doan & Gray, 1992). Based on Janoff-Bulman's specificity hypothesis, this might hold true only for the very specific belief in control over the cure of cancer and not for more flexible general beliefs in control. The current longitudinal study aims to gain more insight in the adaptiveness of specific personal control over cure as opposed to the adaptiveness of generic personal control over life in women with breast cancer who are confronted with a setback after surgery.

Underlying beliefs of control over cure

To interpret the findings regarding the adaptiveness of cancer-specific control perceptions and to understand their meaning, it is important to understand *how* women believe they can personally exert control over cancer. Most studies that examined cancer-specific control perceptions included written self-report measures with one or more items about perceived personal control over central illness aspects, like the course, cure or recurrence of disease. Many of these studies show *that* patients perceive control over the disease, but often it remains unclear *how* patients believe they can exert control (Tomich & Helgeson, 2006; Carver et al., 2000; Malcarne et al., 1995; Stanton & Snider, 1993). Studies that did examine perceived control strategies showed that a sense of control can be based on very different beliefs, e.g., a belief in the effectiveness of a healthy life style, a positive attitude, prayer or compliance with treatment (Stewart et al., 2001; Thompson, Sobolew Shubin, Galbraith, & Schwankovsky, 1993; Lowery et al., 1993; Taylor et al., 1984). The adaptiveness of control beliefs might depend on such underlying beliefs. If patients believe in the influence of a positive attitude on tumor growth, they might feel responsible and incompetent (Doan & Gray, 1992) when faced with a setback. On the other hand, if patients perceive control through compliance with treatment, they might feel they did everything they could. For illustrative purposes, the beliefs underlying a sense of control in our sample of newly diagnosed breast cancer patients will be presented.

Correlates of control over cure

To more fully understand the adaptiveness and meaning of perceived control over the cure of breast cancer, knowledge about the correlates of such perceptions is needed as well. According to cognitive adaptation theory, the generation of a sense of control over the disease reflects an *adaptive response* to stress. Based on this theory, it can be expected that a sense of control over cancer is associated with other adaptive personal resources, like optimism, a strong sense of control over life in general, and low neuroticism. Besides an indication of an adaptive response, a strong sense of control might also be motivated by a strong *need* for personal control after a cancer diagnosis (Kelley, 1971). Cancer is characterized by high levels of uncertainty and ambiguity and, additionally, it poses a substantial threat to life itself as well as to highly valued goals in life (Fleer & Scheier, submitted). Findings from both laboratory and field studies suggest that under such circumstances, when stress levels are high and when important outcomes are at stake, people are often inclined to overestimate their possibilities for control (Thompson, Armstrong, & Thomas, 1998; Taylor & Armor, 1996; Friedland, Keinan, & Regev, 1992). With this line of reasoning, the strongest control perceptions would be expected in patients facing the most threat. Findings of Malcarne et al. (1995) supported this notion, i.e., patients with cancer in an advanced stage reported the highest degree of control. Furthermore, a strong dispositional need for control might inspire exaggerated control perceptions after a cancer diagnosis as well. Burger & Cooper (1979) demonstrated that only subjects with a high desire for control displayed a belief in personal control over chance outcomes. In sum, insight into the profile of patients with a strong sense of control over cancer might allow for a more meaningful conclusion about the adaptiveness and meaning of such beliefs.

Study aims

First of all (*Aim 1*), this study aims to test the effect of a setback after surgery on the adaptiveness of control over cure. Based on theory, (*1a*) it was hypothesized that disappointing news after surgery either *enhances* the adaptiveness of personal control over cure, as the situation poses more threat; or *reduces* the adaptiveness of personal control over cure, as the belief in personal influence is disconfirmed. Moreover (*1b*), to test Janoff-Bulman's specificity hypothesis, we contrasted the moderating effect of disappointing news on the adaptiveness of *specific* control over cure with it's effect on the adaptiveness of *generic* control over life. These hypotheses were tested longitudinally, by examining the relation between personal control pre-surgery (T0) and changes in both general and cancer-specific psychological outcome measures right after surgery (T1) and two months after the end of treatment (T2). Second, to interpret the findings, (*Aim 2*) patients' beliefs about the exertion of personal control were explored. These underlying beliefs were based on qualitative reports and serve an illustrative purpose only. Third, (*Aim 3*) the correlates of cancer-specific control were examined by relating control over cure to various patient characteristics. Based on theory, it was hypothesized that (*3a*) a strong sense of control over cure is related to protective traits reflecting the capacity to adapt to adversity (optimism, general control over life and low neuroticism) or to (*3b*) characteristics that reflect the need for control (cancer stage, prescription of chemotherapy, desirability of control). In addition, we explored the relations with several demographics (educational level, religiosity and age).

7.2 Methods

Procedure

Six hospitals in the Northern part of the Netherlands were involved in the recruitment of respondents. The study protocol was approved by the Medical Ethical Committees. Women who were referred to the hospital because of a suspicion of breast cancer were invited to participate. Women were eligible if they (1) were 75 years old or younger, (2) did not have a serious psychiatric disorder or a somatic disorder that implied hospital admission, (3) comprehended Dutch, (4) followed the usual diagnostic protocol and (5) did not have a history of cancer. The present paper reports on the data of women who were diagnosed with a malignant breast tumor. All women were treated with curative intent. The timing of assessments was linked to meaningful events, i.e. diagnosis, surgery, adjuvant treatment and end of treatment (Heim, Valach, & Schaffner, 1997). To avoid heterogeneity in the order of these events, 10 patients treated with neo-adjuvant chemotherapy were excluded from the study. This paper reports on three assessments: before surgery (T0), shortly after surgery (T1) and two months after the end of complete treatment (T2).

Sample

A total of 3093 women were invited to the study prior to diagnosis, of whom 1226 gave informed consent (40%), of whom 1094 were eligible. Of these 1094 women, 912 women were contacted within 6 weeks after diagnosis and confirmed their initial consent. Of these 912 women, 242 women were diagnosed with breast cancer. To examine the adaptiveness of personal control in the face of setback, we limited our primary analyses to women who completed all three assessments at the appropriate times (n = 133).[1] To examine the correlates of personal control over cure and the perceived ways to exert control, we used data from all women who completed the personal control over cure scale at T1 (n = 228, of whom 224 were interviewed at home).

The sub-sample of 133 women 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 sub-sample (M = 57, SD = 9, n = 133) is 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) resembles 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 sub-sample, 73% was treated with radiotherapy and 40% was treated with chemotherapy, compared to respectively 69% and 39% regionally. The larger sample (n = 228) was largely similar to the regional population as well.

As assessments were linked to events and depended on prescribed treatment, time since diagnosis at each assessment differed between subjects. In the sub-sample (n = 133) the median number of days since diagnosis was 11 days at T0, 52 days at T1 and 180 days at T2.

News after surgery

News after surgery was considered to be disappointing when pathology results indicated that chemotherapy was necessary. Chemotherapy is prescribed when prognostic characteristics are relatively unfavorable (i.e., when the tumor is larger, more aggressive or has spread to the lymph nodes). In contrast to abstract information about tumor size, tumor grade or node involvement, the message that chemotherapy is necessary has concrete meaning for patients. For this reason, we believe that the necessity of chemotherapy is the most suitable indicator of bad news about disease severity from the patient's perspective.

Instruments

Personal control

The 6-item personal control scale of the Revised Illness Perception Questionnaire (Moss Morris et al., 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996) was revised to reflect personal control over cure ('my illness' was replaced by 'the cure of my breast cancer'). An example item is: 'The cure of my breast cancer depends on me'. Alphas were .76 (T0; n = 131) and .79 (T1; n = 228). Personal control over life was assessed with the 7-item Mastery List (Pearlin & Schooler, 1978) reflecting perceived personal control over events and situations in life. An example item is: 'What happens to me in the future mostly depends on me'. Alphas were .82 (T0; n = 132) and .86 (T1; n = 227). Both instruments used a 5-point Likert scale.

Generic psychological outcomes

Depressive symptoms were assessed with the Center for Epidemiologic Studies Depression scale (Bouma, Ranchor, Sanderman, & van Sonderen, 1995; Radloff, 1977). Respondents rated how often they experienced each of 20 symptoms during the past week on a 4-point scale. Alphas ranged from .86 to .92 (T0-T2; n = 126 - 129). Anxiety was assessed with the 6-item short version of the state scale of the Spielberg State and Trait Anxiety Inventory (Marteau & Bekker, 1992; Spielberger & Gorsuch, 1970). Respondents were asked to rate the degree to which they were currently experiencing each anxiety symptom on a 4-point scale. Alphas ranged from .86 to .88 (T0-T2; n = 130-132).

Cancer-specific psychological outcomes

Worries over cure were assessed with three items based on the Cancer Worries Scale (Lerman et al., 1991). The original items ask about worries over one's chance of having cancer and the influence of these thoughts on mood and daily activities on a 4-point scale. Instead, our revised items ask about worries over the cure of breast cancer. Alphas ranged from .78 to .83 (T0-T2; n = 132-133). Threat appraisal was assessed with ten items based on an item set of Vinokur et al. (1990), asking about worries over the impact of breast cancer on important life domains (e.g. daily activities, romantic life, relationship with friends) on a 4-point scale. Alphas ranged from .88 to .89 (T0-T2; n= 122-131).

Possible correlates of control over cure

Dispositional desirability of control over events in life was assessed with the 20-item Desirability of Control scale (Gebhardt & Brosschot, 2002; Burger & Cooper, 1979). Alpha was .79 (T1; n = 227). Neuroticism was assessed with the five 12-item subscales of the NEO-Five Factor Inventory (Hoekstra, de Fruyt, & Ormel, 2003; Costa, Jr. & McCrae, 1992). Alpha was .87 (T1; n = 227). Optimism was assessed with the 6-item Life Orientation Test-Revised (Scheier, Carver, & Bridges, 1994). Alpha was .74 (T1; n = 224). All three instruments used a 5-point scale.

Analysis

Age was included as a confounder, as age was negatively related to both the prescription of chemotherapy and personal control, while positively to some of the psychological outcomes. First, the cross-sectional Pearson correlations between personal control over cure and life at baseline (T0) and the outcome measures at all occasions were examined for the full sample and for women who were and who were not treated with chemotherapy, controlling for age. To test the moderating effect of news after surgery on the adaptiveness of control beliefs (*Aim 1)*, we performed hierarchical regression analyses for the four outcome measures at T1 and T2 separately, once including *control over cure* at T0 and once with *control over life* at T0. As we were interested in changes in the outcomes after the communication of news after surgery, and wanted to take into account pre-existing differences, the baseline level of the outcome was entered in the first step. Age was entered in the second step, news after surgery and personal control in the third and fourth step, and the interaction between personal control and news in the fifth step. To avoid multicollinearity, personal control was centered around the mean (Aiken & West, 1991). The regression coefficients of the two final steps will be presented. As in total 16 regression analyses were performed, the possibility of finding effects by chance was taken into account when interpreting the results.

To examine women's ideas about ways to exert control over cure (*Aim 2*), the answers to the open-ended question that were recorded by the interviewer were coded into categories by two independent raters. The categories were based on the analysis of an arbitrary selection of 20 interviews. When assigned codes differed between the two raters, the answer was discussed until agreement was reached. Women often named more than one category. To characterize women with a strong sense of control over cure, results are presented separately for patients within the highest 30% and the lowest 70% of scores on the 6-item control over cure scale at T1. Differences were examined by means of Chi^2 tests.

Lastly, we examined Pearson correlations between personal control over cure after surgery (T1) and age, dispositional desirability of control, personal control over life, neuroticism and optimism. The relations between personal control over cure and educational level, religiosity, cancer stage and the prescription of chemotherapy were examined by analyses of variance. We subsequently performed a multivariate regression analysis with all significant correlates as predictors, to examine which characteristics were uniquely related to personal control over cure (*Aim 3*).

Table 7.1 *Partial Pearson correlations between personal control over cure (T0), personal control over life (T0) and the generic and cancer-specific outcomes, controlling for age*

		Control over cure T0			Control over life T0		
		No CT	CT	Total	No CT	CT	Total
T0	Depression	-.15	-.44†	-.24†	-.52†	-.62†	-.57†
	Anxiety	-.12	-.43†	-.22*	-.46†	-.61†	-.51†
	Appraisal	-.28*	-.27	-.25†	-.59†	-.33*	-.48†
	Worries	-.15	-.38†	-.21*	-.45†	-.48†	-.47†
T1	Depression	-.14	-.50†	-.26†	-.44†	-.50†	-.47†
	Anxiety	-.16	-.45†	-.24†	-.43†	-.45†	-.41†
	Appraisal	-.22	-.36†	-.23†	-.38†	-.32*	-.35†
	Worries	-.06	-.45†	-.20*	-.27*	-.37†	-.31†
T2	Depression	-.08	-.26	-.11	-.45†	-.30*	-.39†
	Anxiety	-.02	-.43†	-.18*	-.44†	-.44†	-.45†
	Appraisal	-.10	-.32*	-.17	-.42†	-.41†	-.42†
	Worries	.09	-.37†	-.07	-.18	-.35*	-.25*

No CT = no chemotherapy prescription, CT = chemotherapy prescription. As a results of incomplete cases, the n in the total sample varies between 127 - 129, in the sample not treated with chemotherapy between 76 - 77 and in the sample treated with chemotherapy between 48 - 49.
* p<.05; † p<.01

Table 7.2 *Results of hierarchical regression of generic psychological outcomes on personal control over cure and life, controlling for age and the level of the outcome at T0* [a]

	Predictor	Depressive symptoms						Anxiety					
		T1			T2			T1			T2		
		β_{step4}	β_{step5}	ΔR^2	β_{step4}	β_{step5}	ΔR^2	β_{step4}	β_{step5}	ΔR^2	β_{step4}	β_{step5}	ΔR^2
1	Outcome T0	$.69^{\dagger}$	$.69^{\dagger}$	$.51^{\dagger}$	$.55^{\dagger}$	$.55^{\dagger}$	$.29^{\dagger}$	$.60^{\dagger}$	$.60^{\dagger}$	$.42^{\dagger}$	$.58^{\dagger}$	$.57^{\dagger}$	$.34^{\dagger}$
2	Age	-.03	-.04	.00	.06	.06	.00	-.09	-.09	.01	-.02	-.03	.00
3	News (CT = 1)	.07	.07	.00	.12	.12	.01	.17*	.18*	.02*	-.10	-.09	.01
4	Control cure T0	-.11	-.04	.01	.01	.01	.00	-.13	-.08	.02	-.05	.05	.00
5	Control x News		-.11	.01		.01	.00		-.09	.00		-.15	.01
1	Outcome T0	$.66^{\dagger}$	$.66^{\dagger}$	$.51^{\dagger}$	$.48^{\dagger}$	$.48^{\dagger}$	$.29^{\dagger}$	$.56^{\dagger}$	$.56^{\dagger}$	$.41^{\dagger}$	$.50^{\dagger}$	$.50^{\dagger}$	$.35^{\dagger}$
2	Age	-.03	-.02	.00	.03	.02	.00	-.07	-.07	.01	-.04	-.04	.00
3	News (CT = 1)	.06	.06	.00	.12	.11	.01	.17*	.16*	.02*	-.08	-.08	.01
4	Control life T0	-.10	-.09	.01	-.13	-.19	.01	-.14	-.15	.01	-.19*	-.21	.03*
5	Control x News		-.02	.00		.08	.00		.03	.00		.03	.00

CT = chemotherapy prescription [a] The n varies between 130 -131 as a result of incomplete cases; * $p<.05$; † $p<.01$

Table 7.3 *Results of hierarchical regression of cancer-specific psychological outcomes on personal control over cure and life* [a]

	Predictor	Threat appraisal						Worries over cure					
		T1			T2			T1			T2		
		β_{step4}	β_{step5}	ΔR^2	β_{step4}	β_{step5}	ΔR^2	β_{step4}	β_{step5}	ΔR^2	β_{step4}	β_{step5}	ΔR^2
1	Outcome T0	$.55^\dagger$	$.55^\dagger$	$.36^\dagger$	$.58^\dagger$	$.58^\dagger$	$.38^\dagger$	$.55^\dagger$	$.54^\dagger$	$.34^\dagger$	$.43^\dagger$	$.43^\dagger$	$.23^\dagger$
2	Age	-.16*	-.17*	$.05^\dagger$	-.18*	-.19*	$.04^\dagger$	-.14	-.14	.02*	-.17*	-.17*	$.06^\dagger$
3	News (CT = 1)	$.21^\dagger$	$.21^\dagger$	$.03^\dagger$	-.06	.07	.00	.07	.08	.00	$.22^\dagger$	$.23^\dagger$	$.04^\dagger$
4	Control cure T0	-.11	-.07	.01	-.02	.06	.00	-.07	.02	.00	-.01	.11	.00
5	Control x News		-.06	.00		-.13	.01		-.14	.01		-.20*	.02*
1	Outcome T0	$.53^\dagger$	$.53^\dagger$	$.36^\dagger$	$.51^\dagger$	$.52^\dagger$	$.38^\dagger$	$.54^\dagger$	$.54^\dagger$	$.35^\dagger$	$.40^\dagger$	$.40^\dagger$	$.23^\dagger$
2	Age	-.16*	-.16*	$.05^\dagger$	$-.20^\dagger$	-.19*	$.04^\dagger$	-.14	-.13	.02*	-.18*	-.16	$.06^\dagger$
3	News (CT = 1)	$.20^\dagger$	$.21^\dagger$	$.03^\dagger$	.07	.09	.00	.06	.07	.00	$.22^\dagger$	$.23^\dagger$	$.04^\dagger$
4	Control life T0	-.10	-.07	.01	-.17*	-.07	.02*	-.06	-.02	.00	-.08	.03	.00
5	Control x News		-.03	.00		-.14	.01		-.06	.00		-.16	.02

CT = chemotherapy prescription [a] The n varies between 129 -131 as a result of incomplete cases; * $p<.05$; † $p<.01$

7.3 Results

Adaptiveness of control over cure

In the total sample (Table 7.1), the negative relation between a sense of control *over cure* at baseline (T0) and the generic and cancer-specific outcomes (T0-T2) was weak, but in most instances significant. These cross-sectional correlations were generally more negative in women who were prescribed chemotherapy (n = 52; 39%) than in women who were not (n = 81; 61%). Noteworthy, thisdifference was already present at T0, before the communication of the necessity of chemotherapy. In addition, a strong sense of control *over life* at baseline (T0) was negatively related the outcomes at all occasions. These correlations were generally of medium size and did not seem to be dependent on chemotherapy prescription.

The results of the longitudinal regression analyses are presented in Table 7.2 (generic outcome measures) and Table 7.3 (cancer-specific outcome measures). Chemotherapy prescription after surgery predicted more threat appraisal and more anxiety right after surgery (T1) and more worries after the end of treatment (T2). Personal control over cure did not have a main effect on any of the outcomes. The effect of personal control over cure on worries at T2 did however depend on the news patients received, i.e. control over cure was negatively related to worries in women who were prescribed chemotherapy ($\beta = -.20$, $p = .10$) and positively in women who were not ($\beta = .11$, $p = .25$). These simple slopes (main effects) within each group were however non-significant. The effect of personal control over

Table 7.4 *Answers to the open-ended question about ways to exert control over cure*

	Total		Highest 30%[a]		Lowest 70%[a]	
	n	%	n	%	n	%
Positive attitude	76	34%	33	50%†	43	27%
Adherence	76	34%	23	35%	52	33%
Life style	38	17%	16	24%*	22	14%
CAT	2	1%	1	2%	1	1%
Different way	13	6%	6	9%	7	4%
No or very little control	74	33%	7	11%†	67	42%
No answer	6	3%	0	0%	6	4%
No answer, expressing hope	10	5%	4	6%	6	4%
Total n	224		66		158	

CAT = Complementary or alternative treatment.

[a] Patients within the highest 30% (>20) or lowest 70% (<=20) of scores on the 6 questionnaire items about personal control over cure filled out before the interview; Chi2 tests. * p<.05; † p<.0

cure on all other outcomes was independent of chemotherapy prescription. Personal control over life in general (T0) predicted less anxiety and less threat appraisal at T2. The effect of personal control over life on all outcomes was independent of chemotherapy prescription.

Underlying beliefs of control over cure

Table 7.4 shows the response categories for the open-ended question about ways to exert control over cure after surgery (T1). One in three women believed that a positive *attitude* (e.g., optimism, humor, hopeful thoughts) had an effect on the cure of breast cancer. This belief was reported more frequently by women with the strongest sense of control. A third of the women indicated they could affect cure by *adherence* (e.g., agreeing with treatment, attending clinic visits). A belief in the effectiveness of adopting a healthy *life style* (e.g., healthy diet, physical activity, fresh air, avoiding stress) was more common among women who reported a strong sense of control over cure. One third reported to have *no or very little control* over the cure of breast cancer; logically this was most

Table 7.5 *Means and F-test results for differences on personal control over cure after surgery (T1) based on educational level, religiosity, disease stage and prescription of chemotherapy (n = 228)*

	N	%	Personal control over cure	F	Sig.
Educational level					
low	93	41%	18.3 (4.0)	2.565	.08
intermediate	76	33%	18.4 (4.6)		
high/academic	59	26%	19.7 (3.2)		
Religiosity					
no	128	58%	18.5 (4.4)	0.858	.36
yes	93	42%	19.0 (3.6)		
missing	7				
Cancer stage					
0	20	9%	16.5 (3.0)	2.843	.04
1	84	37%	19.0 (3.7)		
2	98	43%	18.7 (4.3)		
3	24	11%	19.8 (4.5)		
missing	2				
Chemotherapy					
no	124	54%	18.4 (3.8)	1.441	.23
yes	104	46%	19.0 (4.3)		

common among women with a lower sense of control. Yet, 37% of these women at the same time provided an answer that fell into one of the above mentioned categories. Ten women did not provide an answer to the question, yet they explicitly expressed a sense of hope for or faith in cure ('It will be all right', 'I expect the best').

Correlates of control over cure

There was a significant relation between personal control over cure (T1; n = 228) and disease stage (Table 7.5). Contrast tests showed that women with cancer in stage 0 (in situ) reported a lower level of control over cure than women with cancer in higher stages (1-3). The level of personal control over cure in women with cancer in stage 3 was highest, but did not differ significantly from that in women with cancer in stage 1 or 2. Educational level, religiosity and the prescription of chemotherapy were unrelated to personal control over cure. Table 7.6 shows that there was a *strong* positive correlation (Cohen's d >= .8; r >= .37) between personal control over cure and both personal control over life and optimism. Furthermore, women with a high sense of control over cure had lower scores on neuroticism (*moderate*, Cohen's d >= .5, r >= .24), were younger and had a slightly higher general desire for control (*weak*; Cohen's d >= .2, r >= .10).

The characteristics significantly related to personal control over cure were entered simultaneously in a multiple regression analysis. Three dummy variables representing cancer stage were included, with stage 3 as the reference category. The complete set of characteristics explained 28% of the variance in personal control over cure. Personal control over life (β = .35, p < .001), optimism (β = .25, p < .01), age (β = -.12, p = .04) and cancer stage 0 (β = -.18, p = .02) were independently related to personal control over cure.

Table 7.6 *Pearson correlations between control over cure after surgery (T1) and personal characteristics*

	Personal control over cure
Age	-.17*
Personal control over life	.46†
Desirability of control	.14*
Neuroticism	-.27†
Optimism	.41†

* p<.05, †p<.01 ^{a} The n varies between 224-228 as a result of incomplete cases.

7.4 Discussion

Whereas cognitive adaptation theory suggests that personal control acts as a stress buffer when faced with a setback, other researchers argued that maladaptive outcomes occur when an exaggerated sense of control is disconfirmed. Combining both possibilities, Janoff-Bulman suggested that general beliefs about the self are adaptive at all times, while specific beliefs are vulnerable to disconfirmation. In the current study, we found no evidence that disappointing news after surgery either enhanced or reduced the adaptiveness of a *specific* sense of control over the cure of breast cancer nor that of a *general* sense of control over life (*Aim 1*). Control over cure was often based on the belief that a positive attitude promotes cure, which is consistent with the trend in media portrayals (*Aim 2*). Other perceived ways to personally influence cure were adherence to doctor's prescriptions and adopting a healthy life style. Furthermore, a belief in personal control over cure appeared to be, most of all, a reflection of the capacity to adapt (*Aim 3*). Women with a strong sense of control over cure were best characterized by high optimism and a strong sense of control over life, both key resources in the cognitive adaptation framework. Moreover, a strong sense of control over cure was reported more often in women with invasive cancer than in women with cancer in situ, which might point to the role of a strong need for control.

Both general as well as cancer-specific personal control perceptions were negatively related to the outcomes, although these *cross-sectional* relations were stronger for control over life than for control over cure. Moreover, control over cure seems to be more strongly related to the outcomes in women who were prescribed chemotherapy than in women who were not. The finding that this group difference was already present before news was delivered (T0), suggests that women already knew good or bad news was about. However, women who would receive a chemotherapy prescription did not differ from women who would not on any of the psychological outcomes at baseline (T0). Furthermore, they did respond to the actual news with an increase in anxiety and threat appraisal (T1). For this reason, it is hard to explain that differences in the strength of the relationship already exist at T0. Nevertheless, the cross-sectional correlations suggest a more adaptive effect of control over cure in women who (would) receive bad news.

Whilst control perceptions were cross-sectionally related to the outcomes, only personal control over life could *longitudinally* predict changes after the delivery of good or bad news (i.e., women with a strong sense of control over life reported less anxiety and less worries two months after the end of treatment, controlling for baseline). However, the main finding of this study was that, except for a weak interaction effect on worries over cure at T2, all longitudinal relationships between control and the outcomes were independent of news after surgery. Nevertheless, in line with the cross-sectional findings, the longitudinal findings do suggest a trend toward a more adaptive affect of personal control in women who were prescribed chemotherapy than in women who were not. This non-significant trend supports the cognitive adaptation theory and seems to be more in line with studies showing that the adaptiveness of a general sense of control (Henselmans, Sanderman, Baas, Smink, & Ranchor, 2009) and of *realistic* disease-specific control perceptions increases with disease severity (Helgeson, 1992; Affleck et al., 1987; Folkman, 1984) than with studies showing that the adaptiveness of *unrealistic* disease-specific control perceptions decreases after a setback (Helgeson, 1999; Christensen et al., 1991).

There could be several explanations for our lack of evidence for a longitudinal moderating effect of a chemotherapy prescription. First of all, possibly not all patients interpreted the necessity of chemotherapy as bad news. Doctors sometimes present chemotherapy in a positive manner (i.e., as a preventive measure). Moreover, even though the necessity of chemotherapy is an indicator of relatively severe disease, chemotherapy also provides a way to influence cure. Perhaps the only true bad news is an eventual recurrence of cancer or the news that there are no more treatment options available. However, in the early phase of the illness trajectory, the communication of pathology results and the treatment plan is the only instance of feedback about prognosis. As a chemotherapy prescription at this point in time did increase anxiety and threat appraisal, it seems to be a suitable indicator of bad news in this phase. Nevertheless, future studies should examine how patients interpret a chemotherapy prescription and how such perceptions affect adjustment.

Second, assuming that the prescription of chemotherapy can be considered bad news, the effect of this bad news on the adaptiveness of personal control can be twofold, as is reflected in our two opposing hypotheses. Possibly, the direction of the moderating effect of bad news differed across individuals, which might have caused the null-finding at the group level. The direction of the effect might have depended on the beliefs underlying control over cure, which were shown to differ across patients in the current study. Our qualitative data on underlying beliefs, based on open-ended and unstructured interview questions, did however not allow for the analysis of three-way interactions.

Lastly, perhaps bad news affects the adaptiveness of a sense of control only when control is expressed in active efforts to influence cure (Skinner, 1995). The period between diagnosis and surgery is too short to assume that women actively attempted to influence cure by for example alternative treatment or diet. Future research might focus on the adaptiveness of active efforts to control cure.

Based on the results from the face-to-face interview, we can conclude that 1 in 3 women believed that a positive attitude promotes the cure of breast cancer. Noteworthy, our findings show that women who belief in control over cure also *have* the most optimistic attitude. Our findings are in line with results of earlier studies (Thompson et al., 1993; Lowery et al., 1993). For example, in a study of Stewart et al. (2001) among breast cancer survivors, 60% reported that a positive attitude would prevent breast cancer from recurring. Apparently, many women believe cancer remission can be achieved by adopting a heroic stance towards cancer, i.e. be keeping up hopes, positive thoughts and a fighting spirit. The beliefs underlying such a heroic stance can be twofold (Doan & Gray, 1992). The *strong* formulation implies that mental states have a direct impact on tumor growth, while the *weak* formulation implies that mental states have an indirect influence, through for example greater persistence with treatment. More in-depth research into the beliefs underlying a heroic stance might be interesting, as such knowledge would tell us more about the illusory character of such control beliefs.

Women with a strong sense of control over the cure of breast cancer had various protective characteristics. They were optimistic, had a strong sense of control over life and had lower scores on neuroticism. Furthermore, women with invasive cancer reported higher levels of control over cure than women with breast cancer in situ. This might suggest that a strong need for control, created by disease characteristics, enhances exaggerated control perceptions. However, personal control over cure was only weakly related to the dispositional need for control. Future research might focus on the relationship between perceived personal control and the need for personal control based on situational characteristics as well as on disposition.

The current study has several limitations. First of all, many women were not able to complete the assessment before surgery (T0) and, consequently, we had to drop them from the primary analyses. These women reported more depressive symptoms at T1 than women with complete data, which indicates the possibility of some bias. However, there were no differences with respect to other psychological outcomes at the various points in time. Furthermore, the selected sub-sample of 133 women was shown to be rather representative of the regional population of breast cancer patients. Nevertheless, the final sample was small, which limited the power to detect small moderating effects of chemotherapy prescription. Second, based on the current study, we can only draw conclusions regarding the adaptiveness of personal control over the cure of breast cancer in the early, curative stage of the illness. Our study does not allow for conclusions about the adaptiveness of such control perceptions in case of cancer in a terminal stage.

In sum, the results of our study do not give reason to assume that strong cancer-specific control perceptions in newly diagnosed patients treated with curative intent should be altered because of potentially maladaptive effects. In contrast, patients with the strongest control perceptions might be those best able to adjust to a cancer diagnosis and subsequent setbacks. These insights might help clinical workers in deciding how to respond to patients who report a strong sense of personal control over the cure of the disease.

Footnotes

[1] Women who dropped out after T0 or T1 (n = 29), who missed the baseline assessment T0 (n = 51), who completed T0 only after surgery (n = 12) or who completed T1 only after the first course of chemotherapy (n = 17) were excluded from the primary analyses. The 109 respondents with incomplete data reported more depressive symptoms at T1 than the 133 respondents with complete data. There were no differences with regard to age, treatment modalities or other psychological characteristics at any point in time.

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Chapter 8

Tenacious goal pursuit and flexible goal adjustment scales: a validation study

Resubmitted

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Summary

Objective & Methods. The flexible goal adjustment (FGA) and tenacious goal pursuit (TGP) scales are used regularly in aging and developmental research. The current study examined their validity in a sample of 517 women (30-75 years) in multiple ways.

Results & Conclusions. Overall, the findings show that the scales do not clearly distinguish between FGA and TGP. The direction in which the items were formulated was just as important as what was being measured. Moreover, face validity of particularly the reverse coded items appeared to be weak. The authors recommend a revision of the concept definitions as well as of the items.

Numbering of assessments in this chapter compared to numbering in original design (Figure 1.1)

Chapter 8	T1
Original design	T3

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8.1 Introduction

When growing older, people face many and mostly irreversible losses, such as the loss of function and social roles. Seemingly contradictory, people generally maintain a sense of control, self-esteem and well-being in old age (Fung, Abeles, & Carstensen, 1999; Baltes & Baltes, 1986; Rodin, 1986). The dual process theory of self-regulation (Brandtstädter & Renner, 1990) offers an explanation for this 'well-being paradox' (Poulin, Haase, & Heckhausen, 2005) by assuming a shift from assimilative to accommodative coping strategies when growing older. *Assimilative* coping implies aiming to reach a goal despite difficulties by trying harder or by looking for alternative means. *Accommodative coping* entails changing the desired state by changing the valence assigned to a goal or by looking for an alternative goal. In uncontrollable conditions or when achievement probability is low, assimilative coping strategies can be problematic, as these consume scarce resources and can lead to experiences of failure (Rothermund, 2006). In contrast, accommodative strategies gain in importance under such conditions, as these draw attention 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). Since its development, the instrument has been used regularly in studies on coping with blocked goals due to aging (Heyl, Wahl, & Mollenkopf, 2007; Frazier, Newman, & Jaccard, 2007; Poderico, Ruggiero, Iachini, & Iavarone, 2006; Boerner, 2004; Rothermund & Brandtstädter, 2003; Slangen-de Kort, Midden, Aarts, & van Wagenberg, 2001). The current brief report addresses the validity of the instrument, as only a few researchers explicitly examined if the scales meet their measurement intent (Mueller & Kim, 2004; Heckhausen, 1997),

Empirical findings

A number of studies that made use of the scales provided support for the premises of the dual process theory. As theorized, both coping tendencies were positively related to various measures of psychological well-being (Heyl et al., 2007; Wahl, Becker, Schilling, Burmedi, & Himmelsbach, 2005; Boerner, 2004; Brandtstädter & Renner, 1990). Moreover, in line with theory, only flexible goal adjustment was shown to mitigate the negative effect of unattained developmental goals (Brandtstädter & Renner, 1990) and of various health problems (Heyl et al., 2007; Boerner, 2004; Schmitz, Saile, & Nilges, 1996). Supporting the theorized shift in coping modes, recent studies showed that the negative effects of aging are offset by an increase in flexible goal adjustment at old age (Frazier et al., 2007; Rothermund & Brandtstädter, 2003).

However, not all findings are in line with theory. Inconsistent results are reported regarding the central premise of the dual process theory, i.e. the opposite relation of the two coping tendencies with age (Heyl et al., 2007; Poderico et al., 2006; 2004; Boerner, 2004; Heckhausen, 1997; Brandtstädter & Rothermund, 1994; Brandtstädter, Wentura, & Greve, 1993; Brandtstädter & Renner, 1990). Moreover, findings regarding the interaction between flexible goal adjustment and tenacious goal pursuit differ. Some authors conclude that people with high scores on both tendencies are particularly well off, as after flexible goal disengagement, new goals need to be pursued tenaciously (Heyl et al., 2007; Preiser, Auth, & Buttkewitz, 2005). On the opposite, Bak & Brandtstädter (Bak & Brandtstädter, 1998) concluded that high scores on both scales seem to be maladaptive, possibly because people who tend to use both strategies struggle with a regulatory dilemma, i.e., choosing between holding on and letting go.

In sum, the rationale of the dual-process theory is attractive and it's predictive utility seems promising. However, to interpret sometimes inconsistent findings in empirical studies with more certainty and to further test the theory's premises, a valid instrument is required.

The instrument

Besides the original 1990 paper, not many papers addressed the psychometric properties of the instrument in detail. Generally, only reliability was reported, which was consistently strong for both scales (ranging between .70 and .80). Yet, strong internal consistency is a necessary, but not sufficient condition for validity. Thus far, only Mueller and Kim (Mueller & Kim, 2004) tested the validity of the 30 item questionnaire in detail. They concluded that the English version did not fully support the measurement intent and that item keying, i.e., the direction in which items are formulated, explained more of the variance in scores than did the two coping constructs. Similarly, Heckhausen noticed that the original German version of TGP scale is comprised of two subscales, i.e. one with positively phrased and one with negatively phrased items (Poulin et al., 2005; Heckhausen, 1997). The current brief report addresses the validity and the apparent role of item keying in more detail.

Although the way people cope with disrupted goals is most frequently addressed in aging studies, goal-related coping might play a similar important role in the adjustment to sudden and non-normative life events (Van Damme, Crombez, Goubert, & Eccleston, 2009; Wrosch & Freund, 2001). For this reason, we included the scales in our study on psychological adjustment to breast cancer. In this study, a large reference group of women (30-75 years) who were tested, but turned out not have breast cancer completed the FGA and TGP scales. The data of this sample were used to assess the validity of the instrument.

First of all, we ran a confirmatory factor analysis to test the *factorial validity* of the instrument. We examined three models, i.e. (1) a model assuming only one coping dimension with flexibility and tenacity at opposite poles, (2) a model with the original two orthogonal coping factors, and (3) a model with two keying factors (direct and reverse). Factorial validity would be supported if (1a) the original model with two coping styles shows a good fit, if (1b) this model fits better than the first model assuming only one coping dimension and also better than the two factor model based on item keying, and if (1c) the loadings on the two coping factors are higher than the loadings on the two keying factors. Second, we examined *convergent* and *divergent validity* in a multitrait, multimethod matrix (Campbell & Fiske, 1959). The two different methods used to assess the coping tendencies were compared, i.e. the direct coded items with the reverse coded items. Convergent validity would be supported if (2a) the direct and reverse coded items of the same coping style are strongly related (one construct, different methods). Divergent validity would be supported if (2b) these correlations are stronger than the correlations between the FGA and TGP items measured with items of similar keying (two constructs, similar method). Third, we examined the *face validity* of the items by asking psychology researchers to classify the items. Face validity, the judgement of experts whether the items seem to measure what they are supposed to measure (Streiner & Norman, 2008, page 6), would be established (3) if the expert raters are able to distinguish FGA items from TGP items with sufficient certainty. Together, these three approaches will give more insight in the validity of the instrument designed to assess assimilative tenacity and accommodative flexibility.

8.2 Methods

Sample

Six hospitals in the Northern part of the Netherlands were involved in the recruitment of respondents. Women aged 75 or younger, who were referred to the hospital by their GP for diagnostic tests upon suspicion of breast cancer were invited by mail to participate in the study. When no lump was found or when the lump turned out to be benign, eligible women were included in the reference group. The current study reports on data of this group only.

A total of 3093 women were invited to the study before diagnosis, of whom 1226 gave informed consent, of whom 1094 were eligible. Of these 1094 women, 912 women confirmed their initial consent after diagnosis, of whom 670 did not have cancer (no or a benign abnormality). This paper reports on the assessment at about 6-8 weeks after diagnosis. A total of 517 women completed all items of the coping questionnaire at this point in time.

Instrument

The instrument assessing the tendency to use *tenacious goal pursuit* (TGP) and *flexible goal adjustment* (FGA) when faced with goal disruption (Brandtstädter & Renner, 1990) is comprised of two scales of 15 items each (Table 4). Respondents rate the degree to which they agree with each statement on a five-point Likert scale ranging from '*fully disagree*' to '*fully agree*'. The TGP scale consists of 6 direct keyed and 9 reverse keyed items; the FGA scale consists of 11 direct keyed and 4 reverse keyed. Two bilingual persons independently translated the original German items into Dutch and then compared the two versions together with one of the researchers. Differences between the versions were resolved and the resulting Dutch version was checked on fluency and comprehensibility by three independent Dutch-speaking persons (Werner & Campbell, 1970, the parallel blind technique). The Cronbach alphas of the coping scales indicated acceptable internal consistency of both 15-item scales (TGP = .75; FGA = .83), in line with other reports.

Analyses

First, the factor structure of the coping questionnaire was tested by means of Confirmatory Factor Analysis (CFA) using LISREL version 8.51. As the multivariate normality assumption was not met, we applied the Robust Maximum Likelihood estimation method. Three models were tested; correlations between factors were allowed. In line with common recommendations (Diamantopoulos & Siguaw, 2000), several indexes were used simultaneously to assess model fit: the Satorra-Bentler Chi-square as an index of exact fit, the Root Mean Square Error of Approximation as an index of close fit, the Comparative Fit Index as an index of fit compared to the 'null-model' and the Standardized Root Mean Square Residuals as an index of the size of the residuals. Moreover, the completely standardized factor loadings in model 2 and 3, which indicate the correlation between the item scores and the underlying factor, were compared.

Second, a multitrait multimethod matrix was generated with Pearson correlations between the sum scores on the 11 direct keyed FGA items, the 4 reverse keyed FGA items, the 6 direct keyed TGP items and the 9 reverse keyed TGP items.

Third, face validity was assessed by asking 10 co-workers (with on average 11 years of psychology education or research experience, range 5-40 years) to evaluate the items. In the original text on the development of the scales, it was stated that (Brandtstädter & Renner, 1990) 'One group of items indicated *a tendency to tenaciously pursue goals even in the face of obstacles and under high risk of failure (or, at the opposite pole, the tendency to give up readily)*. According to our formulation, this tendency corresponds to an assimilative mode of coping or control. A second group of items indicated a *tendency to positively reinterpret initially aversive situations and to relinquish blocked goal perspectives easily (or, at the opposite pole, difficulty or reluctance in withdrawing emotionally from barren commitments)*. This tendency obviously corresponds to an accommodative coping style.' The phrases in italic were presented to the raters, both in Dutch as well as in English. They were asked to classify each item to belong to either FGA or TGP (or their opposites). Moreover, for each item, they were asked how certain they were of their classification on a 10-point scale from 'pure guess' (1) to '100% sure' (10). Only correct classifications of sufficient certainty (6 or higher) were considered as support for face validity. Ratings with a certainty of 5 or lower were considered too uncertain to take into account.

Table 8.1 *Fit indices of three CFA models*

	df	SB X^2 (p)	RMSEA	CFI	SRMR
Model 1: 1 factor	405	2245.53 (.00)	0.09	0.46	0.12
Model 2: 2 target factors	404	1625.08 (.00)	0.08	0.55	0.12
Model 3: 2 keying factors	404	1551.92 (.00)	0.07	0.58	0.11

RMSEA: < .05 good fit, .05 to .08 reasonable fit, .08 to .10 mediocre fit, > 0.10 poor fit ; CFI: > 95% acceptable fit. SRSM: < .08 acceptable fit

8.3 Results

Sample characteristics

The 517 respondents were on average 50 years old (SD = 10, range 30-75) and finished either basic/lower (43%), intermediate professional (31%) or higher professional/academic education (26%).

Factorial composition

Table 8.1 shows the fit indices of the three tested CFA models. Model 1, assuming one underlying coping dimension, did not fit well, i.e., RMSEA indicated mediocre fit and the CFI and SRMR were not within the acceptable range. The original model 2 fitted somewhat better, i.e., Chi square was lower, RMSEA indicated just reasonable fit and the CFI was somewhat higher. Lastly, model 3, with two factors based on item keying, fitted even somewhat better than the original model. Yet, CFI and SRMR in neither 2 nor in model 3 were within the acceptable range. We examined differences in item's factor loadings (Table 8.2) on the coping (model 2) and the keying factors (model 3). Most items loaded just as strongly on the coping factors as on the keying factors. The direction in which the items were formulated explained a similar percentage of variance in the item scores (mean FGA 31%, mean TGP 19%) as the coping content of the items (mean direct 28%, mean reverse 22%).

Convergent and divergent validity

The MTMM matrix (Table 8.3) shows that the correlations between the direct and reverse coded items of the same coping style (in bold font) were moderate (TGP) or strong (FGA). The correlations between item sets of similar keying (in italics) were however equal to (FGA direct with TGP direct) or even slightly higher (FGA reverse with TGP reverse) than the correlations between sets of items representing the same coping style (in bold font).

Face validity

The 'best' and the 'worst' rater classified respectively 24 and 14 items correctly with sufficient certainty. The 11 direct coded FGA items were generally easy to categorize (Table 8.2), although several raters were uncertain about item 19, 23

Table 8.2 *Factor loadings in model 2 and 3, number of uncertain and certain (correct and incorrect) classifications by 10 raters*

			Factor loadings CFA				Face validity		
No.		Scale	Model 2		Model 3		uncertain	certain	
			FGA	TGP	-	+		correct	incorrect
04	I find it easy to see something positive (..) serious mishap.	FGA	.64			.70	0	9	1
08	When (..) wrong, I can usually find a bright side in a situation.	FGA	.65			.73	1	9	0
15	In general, I am not upset very long about (..) opportunity.	FGA	.63			.59	1	9	0
16	I adapt quite easily to changes in plans or circumstances.	FGA	.68			.61	1	9	0
17	I usually find something positive even when giving up something I cherish.	FGA	.67			.66	0	10	0
19	I usually have no difficulties in recognizing (..) my limits are.	FGA	.51			.47	7	2	1
21	After a serious drawback, I soon turn to new tasks.	FGA	.51			.55	1	8	1
23	If I don't get something I want, I take it with patience. [a]	FGA	.49			.44	5	4	1
24	Faced with a disappointment, (..) other things in life are just as important.	FGA	.70			.63	1	9	0
25	I find that even life's troubles have their bright side.	FGA	.73			.70	1	9	0
29	When I get into serious trouble (..) the best out of situation	FGA	.58			.64	4	6	0
01	When I get stuck (..), it's hard for me to find a new approach.	FGA*	.53		.58		1	8	1
13	I create many problems (..) because of my high demands.	FGA*	.43		.35		5	3	2
26	It is very difficult for me to accept a setback or defeat.	FGA*	.42		.37		2	7	1
30	I'm never really satisfied unless things measure up to my wishes exactly.	FGA*	.23		.25		2	2	6

+ direct coded, - reverse coded; * Reverse coded item; [a] Content of item in German, used for Dutch translation: Wenn ich nicht bekomme, was ich will, sehe ich das auch as eine Möglichkeit, mich in Gelassenheit zu üben..

Table 8.2 *Continued*

			Factor loadings CFA				Face validity		
No.		Scale	Model 2		Model 3		uncertain	certain	
			FGA	TGP	-	+		correct	incorrect
02	The harder the goal is (..), the more appeal it has to me.	TGP		.37		.32	1	8	1
03	I can be very obstinate in pursuing my goals.	TGP		.27		.09	4	5	1
05	When faced with obstacles, I usually double my efforts.	TGP		.41		.55	0	10	0
07	(..) things seem hopeless, I keep on fighting to reach my goals	TGP		.39		.46	3	6	1
27	Even when a situation seems hopeless, I still try to master it.	TGP		.32		.53	1	8	1
28	I stick to my goals and projects even in face of great difficulties.	TGP		.36		.39	1	9	0
06	To avoid disappointments, I don’t set my goals too high	TGP*		.47	.46		2	6	2
09	I tend to lose interest (..) where I cannot keep up with others.	TGP*		.55	.62		3	7	0
10	I find it easy to give up on a goal if it seems difficult to achieve.	TGP*		.50	.52		3	4	3
11	(…) insurmountable obstacles, I prefer to look for a new goal.	TGP*		.71	.75		2	2	6
12	Life is much more pleasurable (..) not expect too much from it.	TGP*		.61	.66		5	3	2
14	(…) tried hard but can not solve a problem, (…) easy (…) leave it unsolved.	TGP*		.05	.09		5	5	0
18	I avoid grappling with problems for which I have no solution.	TGP*		.48	.43		5	5	0
20	(…) can not reach a goal, (…) change my goal than to keep struggling.	TGP*		.60	.54		4	4	2
22	Faced with a serious problem (..) simply pay no attention to it.	TGP*		.48	.48		5	5	0

+ direct coded, - reverse coded; * Reverse coded item;

Table 8.3 *Multitrait multimethod matrix*

	FGA direct	TGP direct	FGA reverse	TGP reverse
FGA direct	1.00			
TGP direct	*.42***	1.00		
FGA reverse	**.45****	-.06	1.00	
TGP reverse	.11**	**.25****	*.33***	1.00

* p < .05, ** p < .01

and 29. Of the 4 reverse coded FGA items, item 13 and item 30 were problematic. To illustrate, 6 raters falsely classified item 30 as TGP.

Similar to direct coded FGA items, most raters classified the direct coded TGP items correctly and with sufficient certainty, although item 3 and 7 posed difficulties. More raters were however uncertain about the reverse coded TGP items (item 12, 14, 18, 20, 22) and some raters even classified reverse coded TGP items as FGA with sufficient certainty (item 6, 10, 11, 12, 20). In sum, these ratings suggest that the direct coded items of both scales generally had the highest face validity.

8.4 Discussion

Since 1990, the flexible goal adjustment (FGA) and tenacious goal pursuit (TGP) scales have been used regularly by researchers interested in how people deal with blocked goals over the life span. To interpret the findings of these studies and to further test the theory's premises, a valid instrument is crucial. Unfortunately, the current study could not confirm the validity of the scales.

First of all, *factorial* validity was not supported. Even though the original two factor structure fitted better than a model assuming one coping dimension, it did not fit well and even somewhat worse than a two factor model based on item keying. In line with earlier findings (Mueller & Kim, 2004), the direction in which the items were formulated explained the same amount of variance in items scores as coping content. Second, and related, the multitrait, multimethod matrix did not support *convergent* nor *divergent* validity, i.e. groups of items with similar coping content correlated just as strongly as groups of items that were similarly keyed. Numerous studies have reported that items with the same keying within one scale tend to cluster (Spector, van Katwyk, Brannick, & Chen, 1997; Marsh, 1996; Kelloway & Barling, 1990). Apparently, people respond differently to reverse keyed items than to direct keyed items. In the current study, this *method* of measurement was just as important as *what was* being measured (Streiner & Norman, 2008, page 265), indicating that the distinction between flexibility and tenacity is rather subtle. Third, *face validity* of particularly the reverse coded items appeared to be weak, i.e. raters were rather uncertain about the reverse coded flexibility items and often classified reverse coded tenacity items as flexibility. For example, 6 out of the 10 raters were (reasonably) certain that TGP item 11, i.e. 'when I run up against insurmountable obstacles, I prefer to look for a new goal' reflected flexibility.

We believe that the lack of validity has it's origins not in item construction, but in concept definition (Brandtstädter & Renner, 1990). The tendency 'to give up readily' (opposite pole of TGP) is hard to distinguish from the tendency to 'relinquish blocked goal perspectives easily' (part of FGA); and both seem opposites of the 'difficulty or reluctance in withdrawing emotionally from barren commitments' (opposite pole of FGA) and the tendency 'to tenaciously pursue goals even in the face of obstacles and under high risk of failure' (TGP). Only the tendency 'to positively reinterpret initially aversive situations' (part of FGA) seems clearly distinctive from TGP. The overlap in definitions causes problems not only when classifying items, but also when imagining real-life situations in which people pursue or let go of goals. For example, suppose Andrew's goal is to run the marathon for the very first time. Unfortunately, he catches a serious flu a week in advance. What if Andrew decides to try and run the marathon anyway? Does this response reflect tenacity or a lack of flexibility?

From what we have learned from the literature on the two coping modes (a clear overview of the theory is provided by Boerner & Jopp, 2007), we believe the answer depends on the attainability of the goal. The activation of either accommodative or assimilative processes when confronted with blocked goals depends in large part on goal attainability, which is determined by both the nature of the blocked goal (e.g., whether or not it concerns a permanent loss or constraint) as well as of the individual's resources required to reach the goal (e.g., time, energy, social support, assistive devices etc.). Goal attainability is hard to establish with certainty in this example, as well as in most real life situations, and will often depend on individual appraisal. Moreover, other factors also determine the activation of either an accommodative or an assimilative coping mode, like the perceived importance of the goal (Brandtstädter & Renner, 1990). Nevertheless, we believe the definition of the two coping concepts could gain in clarity if tenacity would refer to how one generally deals with *goals that are not easily reached* and flexibility to how one generally deals with *goals that are not or no longer attainable*. In the definition of flexibility as the 'tendency to relinquish unattainable goal perspectives easily', it should be stressed that this is done '*by* positively reinterpreting initially aversive situations'. Only then the definition clearly reflects an accommodation of personal preferences to fit with circumstances.

In line with these adjusted definitions, the instrument could be improved by introducing flexibility items with the phrase '*When it turns out I can not or no longer reach my goal or get something I want, I usually...*'. This phrase could then be complemented with items that reflect accommodation, like 'find it easy to see something positive' or 'realize that other things in life are more important'.

Similarly, tenacity items could be introduced with *'When reaching my goal or getting something I want is difficult, I usually…'* , and could then be complemented with items that reflect assimilation, like 'double my efforts' or 'try different ways to reach my goal'.

Several aspects of this study warrant discussion. First of all, as we made use of a self-developed Dutch translation of the instrument, we can not be certain our conclusions pertain to the German or English version. Yet, as our results confirm the findings of Mueller & Kim (Mueller & Kim, 2004), language does not seem to have influenced the results. Nevertheless, we do encourage researchers to replicate our study using different versions. A second possible limitation of this study is that our sample consisted of women only. Although we have no reason to assume that results would turn out differently in a sample that includes men, we can not rule out this possibility.

In sum, the study findings did not support the validity of the flexible goal adjustment and tenacious goal pursuit scales. In our opinion, this lack of validity has it's origins not in item construction, but in concept definition. The definitions of flexibility and tenacity might be improved by including goal attainability, i.e. whether the goal is just difficult or completely out of reach. Moreover, the difference between reaching a fit by either changing the circumstances or by changing personal preferences should be stressed. Based on these findings, we gave some suggestions for a revision of the definitions as well as the instrument. We would like to invite researchers working with the dual process theory of self-regulation to take these suggestions into account and we hope our findings encourage them to rethink the way of defining and measuring the two coping tendencies.

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Chapter 9

General discussion

This thesis was introduced by the observation that already for three decades researchers have addressed psychological issues related to cancer and that breast cancer patients have always been a popular target group in psycho-oncology. Despite this considerable attention, the introduction promised that this thesis would add to the existing knowledge by taking several new approaches to study the course of psychological well-being over the first year after diagnosis as well as the role of perceived personal control in the adjustment process. A complete overview of the results of the thesis is provided in the Summary. In this last chapter, the main conclusions will be discussed in two parts, one part on psychological well-being (9.1) and one on perceived personal control (9.2). Considering the great number of studies on psychosocial issues related to breast cancer, these paragraphs will specifically address the question 'what's new?'. Additionally, practical implications as well as directions for future research will be presented, by addressing the question 'so (now) what?'. Subsequently, methodological strengths, weaknesses and recommendations regarding the sample, design, instruments and analyses will be described (9.3). The last paragraph will list the main conclusions (9.4)

9.1 Psychological well-being after a breast cancer diagnosis

'De bodem van de put bleek dichterbij dan ik dacht'
Respondent during FACT interview

The findings on psychological well-being in the first year after a breast cancer diagnosis will be discussed in two parts, one on the course of negative emotions (9.1.1) and one on the effect of waiting on emotional well-being (9.1.2).

9.1.1 The course of negative emotions

What's new?

This thesis reports on two novel approaches to study the course of psychological well-being after a breast cancer diagnosis. First of all, whereas in most studies change is examined at a group level, in the current study four distinct trajectories in non-specific psychological distress were identified based on individual patterns over the various stages after diagnosis (Jones, Nagin, & Roeder, 2001). There appeared to be a large group of women who experienced no distress at all (36%), a similarly large group that showed a pattern of recovery after the active treatment phase (33%), a small but substantial group that reported a late increase in distress in the re-entry phase two months after the completion of treatment (15%) and a similarly sized group that was chronically distressed (15%).

Second, we examined and compared the trajectories of three different types of negative emotions at a group level. The findings show that, despite a large overlap between these concepts, the various phases after a breast cancer diagnosis did not trigger anxiety, depressive symptoms and non-specific distress to the same degree. The initial response right after diagnosis was mostly characterized by anxiety, which decreased to normal in later phases. Depressive symptoms, on the other hand, were hardly elevated in women with breast cancer and decreased to levels similar to those in the control group after the end of treatment. Lastly, nonspecific distress symptoms (i.e., general symptoms that indicate a discontinuity in normal functioning) were elevated in all stages, mostly right after surgery, and were only normalizing in the short-term survivorship stage. In sum, besides the initial crisis period after diagnosis, the negative affect cancer patients experience might be of a more general kind.

Referring to the quote this thesis started with, contemporary cancer patients might not be the 'psychological wrecks' they were several decades earlier. Due to major medical advances as well as changes in the societal image of cancer, cancer nowadays might not necessarily be a life-threatening traumatic experience with long-lasting psychological consequences (Coyne & Palmer, 2005; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). This might be particularly true for breast cancer, as survival rates have increased to 85% and as experiences of women with breast cancer are well covered in the public media nowadays. An increasing number of studies report that cancer patients experience only somewhat more psychological problems than people from the general population (van't Spijker, Trijsburg, & Duivenvoorden, 1997; Hagedoorn et al., 2008; Bardwell et al., 2006) and that such problems often diminish over time (Hinnen et al., 2008). The findings of this thesis partly confirm this optimistic picture, i.e., (1) breast cancer did not cause psychological problems *in all women per se* and (2) problems often *naturally resolved over time*. However, the findings do not allow for overly optimistic statements. An examination of the course of distinct negative emotions at a group level showed that the period around diagnosis and surgery provoked considerable anxiety and that non-specific distress diminished only half a year after the end of treatment. An examination of distinct patterns of non-specific distress at the individual level showed that, even though a majority reported no distress or only during active treatment, one in three women remained distressed or began to feel distressed in later stages. In sum, even though women with breast cancer show remarkable resilience, the stressors in different stages after a breast cancer diagnosis can be taxing for some. These findings have several implications for research and practice.

So (now) what?

First of all, a natural decline in anxiety, distress and depressive symptoms over the first year does not imply that such psychological problems should go unattended. Negative emotions, even though temporary, might not only negatively affect patients' quality of life (Golden-Kreutz et al., 2005), but also their ability to make informed decisions about treatment (Kessels, 2003) and their adherence to medical advice (DiMatteo, Lepper, & Croghan, 2000). Patients with elevated negative emotions due to cancer might benefit from non-intensive psychosocial interventions, like stress-management training (Phillips et al., 2008) or psycho-education (Poroch, 1995).

Second, our finding that anxiety, depressive symptoms and non-specific distress show different patterns over time, should be taken into account when screening women with breast cancer in order to identify those who might benefit from an intervention. Right after diagnosis, screening with an instrument assessing anxiety might be the best choice. However, in all later stages, but particularly during treatment, screening for elevated non-specific distress levels will detect most patients with emotional problems. As depression was not a frequent response in women with newly diagnosed breast cancer in the first year, single reliance on a depression scale might not be the best alternative in this group. In sum, it might be most effective to screen with an instrument that taps various types of negative emotions (Mitchell, Baker-Glenn, Granger, & Symonds, 2009). In addition, as patterns of distress were shown to differ across patients, screening should take place on more than one occasion, preferably during active treatment as well as in the re-entry phase.

Third, our finding that some patients reported an increase in distress only in the re-entry and short term survivorship phase warrants attention from both clinicians and researchers. Physical complaints due to adjuvant treatment turned to be the only characteristics that could distinguish women who reported late distress from women who were never distressed. Besides such physical complaints, an explorative examination of the qualitative interviews suggests that late distress might reflect a *delayed response* to the hectic period of diagnosis and treatment. One patient clearly illustrated this by indicating that ‘You board on a driving train and if you like it or not, you have to come along. Now (read: after the completion of active treatment) you are back on the platform and you start to wonder: what journey did I take?’. Also *stressors specific to the re-entry phase* might play a role. Women who reported a late increase in distress mentioned aspects like the loss of monitoring by doctors, the fear of a recurrence and – as confirmed by the quantitative findings - physical complaints. Lastly, *stressors not related to the cancer* might be responsible for late distress, e.g., one patient mentioned the illness of a family member. Future quantitative research should test predictors of late distress in a larger sample with more power, as more knowledge on predictors of late distress might enable early detection and prevention. The variety of aspects that might explain distress makes such prediction and prevention however hard.

Fourth, also the finding that a small group of patients reported distress at all stages after diagnosis has implications. Compared to women who reported distress only in the early phases after diagnosis, chronically distressed women were characterized by neuroticism, a characteristic known to enhance ones vulnerability to stress (Hinnen, Hagedoorn, Sanderman, & Ranchor, 2007; Ranchor et al., 2002). It remains unclear if the chronic high levels of distress were due to difficulties in adjusting to cancer or due to previous psychological problems, either triggered by or entirely unrelated to cancer. From the qualitative interviews, it seems that side-effects of treatment (e.g., mood swings due to hormone treatment; fatigue) or complications (e.g., infection of the breast) might play a role as well, yet these did not turn out as predictors in the quantitative analyses. Furthermore, in the interviews, some women with stable high levels of distress mentioned having difficulties coming to terms with the disease and the risk of recurrence (e.g., they registered for psychological treatment specifically focused on cancer). Also events that were not related to cancer could have been responsible for stable high levels of distress (e.g., problems with children, death of loved ones, other health problems than cancer). More research into the risk factors for prolonged distress is needed. Knowledge on rare but strong predictors might be more useful than knowledge on frequently occurring but weak predictors. Clinicians should be aware of late or prolonged distress in follow-up visits with women with breast cancer.

Lastly, this thesis examined individual differences in the course of non-specific psychological distress only. It would be worthwhile to identify distinct trajectories in anxiety and depressive symptoms as well and to examine the relation between individual patterns in these distinct negative emotions. Such relations might provide helpful insights regarding predictors of late or enduring psychological problems. For example, possibly early anxiety peaks are predictive of depressive symptoms later in the illness trajectory.

9.1.2 The effect of waiting

What's new?

Besides observing the emotional impact of the various stages in the illness trajectory *after* diagnosis, this thesis also examined the impact of the uncertain period of waiting *before* the definite diagnosis is known. On the one hand, waiting might increase or prolong uncertainty and distress. On the other hand, waiting might enable patients to adjust and prepare for what is coming (Kievit, 2002). The current study found support for the first assumption, but not for the latter. Even though a speedy diagnosis did not affect well-being after a breast cancer diagnosis, it did shorten the period before the definite bad news which patients perceived as very stressful. Furthermore, in line with earlier findings (Ubhi et al., 1996; Harcourt, Rumsey, & Ambler, 1999), a speedy diagnosis might particularly benefit those who are eventually not diagnosed with a malignancy. Women who had to wait long before they heard the good news were worried and distressed for a longer period of time after diagnosis than women who received the good news sooner. Next to the effect of waiting for diagnosis, we examined the effect of waiting for surgery. Women who had surgery within 2 weeks after a breast cancer diagnosis were not worse or better off after surgery than women who had to wait for a longer period of time. The finding that patients' well-being did considerably improve after surgery, does however seem to provide support for the benefits of short waiting lists.

So (now) what?

Even though guidelines prescribe a prompt diagnosis, there seems to be a trend for more and more extended diagnostic testing. Due to more complex medicine, more sensitive tests, but also out of legal considerations, doctors tend to request additional tests more often, even if these are not prescribed by guidelines. In some cases, this might cause unnecessary delay and, based on our findings, psychological distress in women who are eventually not diagnosed with a malignancy. Hayward (Hayward, 2003) warned for such unwanted effects of technological advances and speaks of VOMIT, victims of modern imaging technology. Medical personnel in breast disease clinics should be aware that women who receive favorable news after a long diagnostic process might not be reassured immediately and might experience prolonged distress. Possibly, some extra attention and information could prevent such worries.

Besides a speedy diagnosis, our results advocate a speedy surgery, as psychological well-being increased only thereafter. However, the following (translated) quote illustrates that, if medically possible, the whishes of the individual patient should be taken into account when planning treatment. 'To be honest, one does not have enough time to fully realize what is happening. I was glad I had a break of a month or two after surgery, before chemotherapy started, so I could let things sink in. The first period was really the hardest. Everything just happened so fast. Right after I got my diagnosis, my surgery was already planned.' Future qualitative research might look into patients' experiences of waiting in more detail.

9.2 Perceived personal control and psychological adjustment

> *'Once I was the subject, now I am the object'*
> Respondent during FACT interview

The findings regarding the role of perceived personal control in the adjustment process will be discussed in three different paragraphs, i.e. one on personal control over life (9.2.1), one on personal control over cure (9.2.2) and one on relinquishing personal control (9.2.3).

9.2.1 Perceived personal control over life

What's new?

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. Despite the apparent lack of control opportunities, many studies have shown that a strong sense of control over life is a valuable personal resource when diagnosed with breast 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). This adaptive effect was confirmed in various chapters of the present thesis. A sense of control over life was shown to be the only unique predictor of patterns in distress, distinguishing women who reported no distress from those who recovered and from those who remained distressed. Moreover, support was provided for the stress-buffering potential of personal control over life, i.e. a low sense of control was more strongly related to distress in patients treated with chemotherapy than it was in women from the general population. Furthermore, a strong sense of control over life predicted a less salient response in psychological distress after diagnosis as well as a decline in anxiety over the course of the illness trajectory.

Besides replicating the adaptive effect of personal control over life, a new element in the current thesis was the identification of variables that could mediate, i.e., explain the adaptive effect of personal control on the initial response to diagnosis as well as the adjustment later on. It was shown that women with a strong sense of control appraised cancer and their personal coping skills less negatively, which made them less vulnerable to distress after diagnosis. Furthermore, women with a strong sense of control seemed to regulate anxiety after diagnosis by remaining engaged in social life (meeting friends, not avoiding visits, paying attention to friends or family).

Perceived personal control over life might not only *regulate* the impact of cancer on psychological well-being, but might also *be affected by* this threatening and stressful event (Pearlin, Lieberman, Menaghan, & Mullan, 1981). Surprisingly few studies addressed this two sided position of mastery in the stress process. Our findings based on the Relationship and Adjustment to Cancer (RAAK) study showed that at a group level, patients did not differ from healthy women regarding their levels of perceived personal control over life. Only patients treated with chemotherapy, who face a longer treatment trajectory and relatively less good prognostic prospects, reported lower control levels. The difference was largest at nine months after diagnosis, which was attributed to problems specific to the re-entry phase. These findings based on the RAAK data could however not be replicated in the FACT study. Box 9.1 provides some more details about the findings on stability of personal control over life that are not reported elsewhere in this thesis. Apparently, most women in the FACT study found ways to deal with the uncontrollable stressors breast cancer brings without losing a sense of control over life. Such maintenance of control has been reported by others (Stiegelis et al., 2003; Penninx et al., 1996) and can be attributed to certain adaptation processes. Possibly, women maintain control through *compensation*, i.e. by shifting attention to or by gaining control over those domains or illness aspects that are still subject to personal influence (Lapmic, 2002). A different explanation can be derived from Cognitive Adaptation Theory (Taylor, 1983). This theory posits that slightly exaggerated ideas about the self and one's role in the world can have an adaptive function. According to this theory, people are thought

Box 9.1 *Loss or Maintenance of Personal Control over Life in the FACT Study*

Loss or maintenance

Even though a general sense of control is considered to be a rather stable trait, negative experiences might cause an adjustment of perceived personal control to lower levels. Studies have reported on lowered levels of personal control due to economic strains (Pearlin et al., 1981), chronic physical conditions (Vilhjalmsson, 1998), a low income (Lachman & Weaver, 1998) and unemployment (Ross & Mirowsky, 1992). Based on such findings, one might expect cancer, an experience characterized by high degree of uncontrollability, uncertainty and unpredictability, to threaten perceived personal control. In a qualitative study of McVey et al. (2001), a lowered sense of personal control was the most frequent reported experience of cancer patients who had a stoma surgery. In a quantitative study, also Ormel et al. (1997) found that cancer patients reported a lowered level of personal control over life. The FACT study started out with this hypothesis, yet results proved otherwise.

At a group level, personal control of women with breast cancer participating in the FACT study was not different from levels in the reference group. Personal control did not change after diagnosis, nor over the various stages in the illness trajectory. As stability at a group level might not imply stability in individual patients, we examined the presence of distinct trajectories in personal control, using the same sample and method as in Chapter 2 of this thesis. A model with 4 trajectory groups seemed to fit the data best. These 4 trajectories, however, all showed stable patterns of personal control from right after diagnosis until 6 months after the end of treatment.

Different from the RAAK study, the course and level of control in the FACT study were independent of the prescription of chemotherapy. This difference is not easily explained. The samples might have differed in disease severity. Yet, as information on cancer stage was not available in the RAAK study, we could not check for these differences. Furthermore, a more widespread implementation of rehabilitation programs in recent years, like 'Herstel & Balans', might have positively affected the sense of control of women treated with chemotherapy in the FACT study (2005-2007), more so than in the RAAK study (2000-2004). We can however only speculate about such explanations.

Mechanisms

In the face-to-face interviews after surgery and in the re-entry phase, we tried to unravel the mechanisms that underlie the maintenance of a general sense of control over life. Interviewers first explained the meaning of a sense of control over life, making use of the items of the Mastery List. Then, women were asked what they did to maintain or regain a sense of control after diagnosis. An often given response was trying to maintain the normal daily activities as much as possible. This answer might confirm the assumption that remaining in control over things in life that still are controllable might *compensate* for the lack of control over the disease situation.

Box 9.1 *Continued*

Next to maintaining daily life as usual, women maintained a sense of control by looking for information, asking questions, seeking social support, working on a positive attitude and a fighting spirit and by ordering their thoughts. Some of these strategies might raise a sense of control over the consequences of the illness, which might also boost one's general sense of control. Not many women explicitly mentioned they tried to exert control over the disease itself. This might indicate that, in contrast to Cognitive Adaptation Theory, exaggerated *central control perceptions* were not responsible for the maintenance of a general sense of control.

In sum, breast cancer in a curative stage does not seem to cause a dramatic loss of control over life in general. Possibly, compensation plays a role in the maintenance of control, yet these findings are of a very explorative nature, and serve as a first illustration only.

to maintain a sense of personal control (as well as optimism and self-esteem) in stressful situations by engaging in *overly positive self-perceptions*. In women with breast cancer, this might be reflected in a strong sense of control over the cure of the disease. Unraveling the mechanisms that underlie the maintenance of a general sense of control is complicated. An attempt to gain some knowledge on this matter was made in the interviews that were part of the FACT study. Box 9.1 provides a glimpse of these explorative findings. Taken these findings together, it can be concluded that newly diagnosed breast cancer does not cause a dramatic loss of control over life in general. As a perceived lack of control and helplessness are closely linked to depression (Seligman, 1972), the maintenance of a sense of control despite the cancer experience seems to match with the earlier reported finding that, in contrast to anxiety and non-specific distress, depressive symptoms were hardly elevated after a breast cancer diagnosis.

So (now) what?

Clearly, women with a low sense of control over life are more vulnerable for psychological problems after a breast cancer diagnosis. So (now) what? Our findings provided insight in the mechanisms that explain *why* women with a strong sense of control responded less strongly and adjusted more successfully to breast cancer. These women had more positive cancer-specific cognitions and reported less disengagement from social life during treatment. These findings imply that distressed patients might benefit from interventions aimed at coping self-efficacy or remaining engaged in social life and that this might be particularly so for those with a low sense of control.

The study showed that, in general, women do not adjust their perception of personal control over life due to a breast cancer diagnosis. Research into the mechanisms underlying such maintenance of control despite adversity is theoretically interesting, but complicated and requires creative research methods, as control is a rather unconscious and abstract concept. One possibility would be the application of 'think aloud' methods (Bloem, van Zuuren, Koeneman, Visser, Sprangers, Koning & Rapkin, 2008). Registering patients' thoughts when filling out questionnaires on personal control over life (e.g., the Mastery List) might provide valuable insights in the underlying cognitive processes.

9.2.2 Perceived personal control over cure

What's new?

This thesis addressed not only the role of a sense of control over life, but also that of a sense of control over cure. While control over life is general, trait-like and might reflect control over many domains of life; control over cure refers to a very specific aspect of the disease. In the breast cancer awareness month of 2007, Karin Spaink, wrote a pamphlet entitled 'breast cancer without decoration', criticizing the glamorous portrayal of breast cancer in the media. She also wondered, just like researchers in health psychology, whether or not a belief in the ability to personally fight and beat cancer is adaptive. From her own experience, she wrote (translated): 'Fighting cancer is not knowing if you will survive, while in the meantime you try to stay on your feet. This takes courage, perseverance and support, but it is totally different from beating cancer. (…) Cancer survivor is an undeserved and inappropriate term. A better term would be lucky bastard.' Similarly, the Dutch swimmer Maarten van de Heijden (golden medal Olympic Games 2008, 10 km) criticizes the emphasis on fighting cancer personally. 'Armstrong (read: Lance Armstrong) describes his battle, how he was fighting, how he felt that he threw up cancer cells. What he basically says,is that it is your own fault when you don't make it. That you didn't fight hard enough. (..) When my cancer was diagnosed, I lay down in the hospital and simply surrendered to the doctors. You always hear those stories that you have to think positively, that you have to fight to survive. This can be a great burden for patients. It has never been proven that you can cure from cancer by thinking positively or by fighting.' (translated from NRC, 8 May 2008).

These two cancer survivors raised a question that also intrigued health psychology researchers. That is, does a sense of personal control over the cure of the disease – for instance by thinking positively - hurt when this belief is not in line with reality? In women with breast cancer, this question is hard to study, as the illness trajectory of breast cancer does not include many instances of feedback about the progress of the illness or the likelihood of cure (unlike for example success or failure of a kidney transplant, see Christensen, Turner, Smith, & Holman, 1991). Only a recurrence clearly communicates that personal attempts to influence cure failed. However, also the disappointing news that chemotherapy is necessary might disconfirm control perceptions and might have a more negative effect on patients who believe they have control over the cure of the disease than on patients who believe cure depends on chance. Patients who believe in a personal influence on cure might not have prepared for such bad news and might attribute the outcome to things they did or did not do (Doan & Gray, 1992) - like keeping up a fighting spirit - which might negatively affect their well-being.

Women prescribed with chemotherapy (in case of an aggressive, spread or a large tumor) reported more anxiety and threat appraisal after surgery than women not prescribed with chemotherapy. This implies that a chemotherapy prescription is often experienced as bad news. This bad news did, however, not limit the adaptiveness of a belief in control over cure. In fact, there was a trend for control over cure to be even more adaptive in women who received a chemotherapy prescription than in women who did not. A strong sense of control over cure seemed to be a reflection of a stress resilient personality characterized by high optimism and a strong sense of control over life in general. However, as women with invasive cancer reported more control over cure than women with breast cancer in situ, control perceptions might be determined by a strong situational induced necessity to feel in control as well.

So (now) what?

Thus, the findings in this thesis do not give reason to assume that a belief in control over the cure of cancer should be addressed because of potentially maladaptive effects. At least, not in women with newly diagnosed breast cancer who are treated with a curative intent. Yet, more research is needed to strengthen and extend this conclusion. First of all, we can only draw conclusions about the first, curative phase of the illness. A study of Tomich and Helgeson (Tomich & Helgeson, 2006) demonstrated that this conclusion might not hold when patients face a recurrence, which more obviously disconfirms control over cure. In addition, we can only draw conclusions about women with breast cancer, not about patients with other types of cancer. Furthermore, we can only draw conclusions regarding a *sense* of control over cure, not regarding *actual actions* aimed a influencing cure. When a strong sense of control is expressed in active attempts to personally affect cure, for example by drastically changing one's diet, maladaptive outcomes might occur after disappointing news. Lastly, the adaptiveness of personal control over cure might depend on the beliefs underlying control over cure, which were shown to differ across patients in the current study. In line with media portrayals of cancer experiences, one in three women believed that maintaining a positive attitude would promote cure. Next to a fighting spirit, accepting treatment and adopting a healthy life style were commonly mentioned. Our qualitative data on these beliefs, based on open-ended and unstructured interview questions, did however not allow for such analyses. In sum, more research should address the question *when* a sense of control over cure is adaptive and when it is not.

9.2.3 Relinquishing personal control: changing the self instead of the world

What's new?

One of the propositions of this thesis is that 'control is not everything and not everything is control'. This proposition was inspired by an insightful paper of Morling and Evered (Morling & Evered, 2006) entitled 'Secondary control reviewed and defined' as well as on the discussion that followed with Skinner on the issue (Skinner, 2007; Morling & Evered, 2007). Almost twenty-five years earlier, Rothbaum and colleagues (Rothbaum, Weisz, & Snyder, 1982) introduced a two process model of perceived control that assumed people can do two things to gain a sense of control, i.e. trying to influence the circumstances through behavioral actions (*primary control*) or accepting the circumstances and adjusting one's personal preferences (*secondary control*). Rothbaum and colleagues reasoned that even though 'attempts to change the world so that it fits the self's needs' are most commonly studied, 'attempts to fit in with the world an to flow with the current' can sometimes resolve a sense of helplessness as well. Many researchers adopted the framework of primary and secondary control; by now the original paper has been cited over 600 times.

Originally, as the label 'control' implies, secondary control strategies were thought to be motivated by the need to re-gain personal control over the environment. In their recent review, Morling and Evered however reasoned that secondary control strategies do not primarily serve the motive to 'be in control', but the motive to 'fit in'. Preventing helplessness and despair might be among the beneficial outcomes of secondary control strategies, but such outcomes are not similar to regaining control over the situation. Skinner (2007) takes this argument even further, and argues that strategies that imply adjusting the self to fit with circumstances should be 'liberated from the domain of control' and should be studied under the label of accommodative processes. Secondary control is more a way of coping than it is a way of maintaining in control. In sum, as the proposition states, maintaining in control is not all important when dealing with adversity, and not everything people do to cope with such circumstances serves the motive to control.

Even though the current study is centered around the concept of personal control, controlling the environment might not be all-important when dealing with the rather uncontrollable circumstances after a breast cancer diagnosis. Accommodative processes, i.e. the adjustment of personal goals and preferences to match with the changed circumstances, might be just as relevant. For example, women who are able to re-appraise the situation in a positive way ('It is actually quite good for me to be at home for some time') might be better off than women who keep on trying to change the circumstances ('No matter what, I will drag myself to work'). For this reason, the FACT study included an instrument that assesses people's general tendency to use accommodative and assimilative coping (Brandtstädter & Renner, 1990), concepts that show conceptual overlap with primary and secondary control. The terms accommodation and assimilation originate from the dual-process theory of self-regulation and can be assessed with two scales, i.e. the Tenacious Goal Pursuit (TGP) and the Flexible Goal Adjustment (FGA) scales. Tenacious Goal Pursuit implies the 'tendency to tenaciously pursue goals even in the face of obstacles and under high risk of failure'. On the other hand, Flexible Goal Adjustment reflects 'the tendency to positively reinterpret initially aversive situations and to relinquish blocked goal perspectives easily'. As the TGP and FGA scales were most often used in ageing or developmental studies, and as not much psychometric work was done with the instrument, we decided to first test the validity of the scales in the reference sample of women who were not diagnosed with cancer. Unfortunately, we could not confirm the validity of the scales. The *method* of measurement, whether items were direct or reverse keyed, was just as important as *what was* being measured. This indicates that the distinction between FGA and TGP in the items was too subtle.

So (now) what?

In our opinion, the validity of the FGA and TGP scales might be improved by including goal attainability, i.e. whether the goal is just difficult or completely out of reach. Moreover, the difference between reaching a person-environment fit by either changing the circumstances or by changing personal preferences should be stressed more clearly. We invite researchers working with the dual process theory of self-regulation to take these suggestions into account and to rethink the way of measuring the two coping tendencies.

The dual-process theory provides an interesting perspective on coping with blocked goals. Accommodative coping strategies might be an important predictor of psychological adjustment to breast cancer and a lot of questions on this process are still to be answered. For example, are women who are using accommodative strategies better able to deal with the uncontrollable consequences of having cancer? In addition, is the tendency to accommodate related to benefit finding (Carver & Antoni, 2004)? Often, cancer patients not only report negative, but also positive consequences resulting from their disease, for example, 'Cancer made me a stronger person'. Benefit finding might reflect a positive re-appraisal of an initially negative situation serving the aim of reaching a better fit between personal preferences and the circumstances. In that sense, people with a strong tendency to accommodate in the face of blocked goals might report more benefit finding than people with strong tendency to assimilate. Knowledge on such relations might increase our understanding of benefit finding. Lastly, it might be interesting to know to what extent accommodative processes are conscious and if patients can learn how to use such strategies. In order to answer these kind of questions, the construction of a valid instrument is needed. This seems to be a major challenge, as the concepts are clear from theory but seem hard to translate in concrete items.

9.3 Methodological strengths, weaknesses and recommendations

This paragraph discusses strengths, weaknesses and recommendations regarding the design, the sample, the instruments and the analyses used in this study.

The design

Compared to earlier studies on adjustment to cancer, the design of the FACT study was rather novel for several reasons. To start with, it included an assessment before diagnosis, providing us with data on perceived personal control, distress and worries before the actual diagnosis was communicated. This enabled us to examine the relation between a sense of control pre-diagnosis and the first emotional response to the definite bad news. Likewise, we could examine the effect of the length of the waiting period before definite diagnosis on this first response in distress and worries. However, several aspects of this baseline measurement warrant discussion. *First of all*, this first assessment can not be regarded as a true baseline measure. When patients were referred for further diagnostic testing in the hospital, distress levels were already elevated, in both women who would and who would not be diagnosed with breast cancer. In fact, in retrospect, many women diagnosed with breast cancer indicated that they believed this period was most stressful when compared to various later stages after diagnosis. In order to collect true baseline data, one would need to assess women before the suspicion of breast cancer is raised. The only feasible way of doing so would be in large population studies, like the Life Lines study that is currently conducted in Groningen and the Groningen Longitudinal Ageing Study (GLAS; Ranchor et al., 2002). *Second*, including a pre-diagnosis assessment complicated research logistics, as becomes clear from the large percentage of patients that missed this first assessment. Hospitals with rather short waiting periods between referral and visit were not able to send an invitation beforehand. *Third*, besides these practical challenges, researchers should keep in mind that careful communication in this period is important. Inviting people to participate in a study about coping with cancer at a time they are not yet certain about their diagnosis is sensitive and should be done with care. Nevertheless, as a semi-baseline, the first assessment gave us interesting research opportunities.

A second unique feature of the FACT study was the choice of assessment points. Based on suggestions of Heim and colleagues (Heim, Augustiny, Schaffner, & Valach, 1993; Heim, Valach, & Schaffner, 1997), the design was not linked to time since diagnosis but to clinically meaningful stages in the illness trajectory, i.e., diagnosis, surgery, adjuvant treatment, re-entry and short-term survivorship. Each of these stages brings along different stressors which might have a larger effect on patient's well-being than the time passed since diagnosis. Or put differently, patients assessed in the same illness stage might be more similar than patients assessed at the same point in time since diagnosis. Our data provided some support for this assumption, i.e., at none of the assessments (linked to illness stage) was time since diagnosis related to measures of psychological well-being. Conclusions regarding illness stages might have more clinical significance than conclusions about various rather arbitrary points in time.

Thus, we would like to encourage researchers to take into account the various stages in the illness trajectory when choosing the design of their longitudinal study. However, we would like to point out some practical challenges and complicating factors related to this design. To start with, we had to make some concessions in order to match the design with the reality of various different treatment trajectories after a breast cancer diagnosis. For example, we decided to exclude the small number of women who received neo-adjuvant chemotherapy, i.e. chemotherapy administered before surgery when the tumor is relatively large. So, results cannot be generalized to this particular group. In addition, we could not be as strict as we would have liked to be with the assessment after surgery. Women were not always able to fill out this questionnaire out before the start of adjuvant radio- or chemotherapy. For this reason, we decided to regard questionnaires filled out after the start of chemotherapy as missing (in those sub-studies that required this), yet we did include questionnaires filled out after the first radiation sessions. Women who received the first sessions of radiotherapy when completing the post-surgery questionnaire did not differ from women who did not yet start on psychological measures. Lastly, we decided to regard the completion of radio- and chemotherapy as 'end of active adjuvant treatment'. This does however not mean that women did not receive any treatment at all thereafter. Of the 242 women, 42% were treated with hormonal therapy, which in most cases implies self-administration of medication for several, usually five years. Because of the considerable duration and an in general relatively low intrusiveness compared to radio- or chemotherapy, it was decided not to take this treatment modality into account in the design of the study. In addition, 12% of the women were treated with trastuzumab (Herceptin), a medicine delivered through an infuse every three weeks for a period of 1 year, often starting after chemotherapy treatment. As also this type of treatment had a long duration, and as it concerns a relatively small group, we decided not take it into account in the design. When controlling for age differences, women treated with hormones and/or Herceptin did not report more negative emotions than women who were not under treatment at the last two assessments (T5 and T6). In sum, it can be concluded that it was hard to define 'end of treatment' in a clear-cut way, so that it applied to all women. The results of this thesis seem largely unaffected by this limitation, yet we do believe that when Herceptin is prescribed more frequently in the future, study designs should take this type of treatment into account. All things considered, even though the design might not perfectly match each individual patients trajectory, we believe it is still a better fit than a time-linked design that does not take stages or treatment status into account at all.

Besides accepting several compromises, the design implied that we had to collect and register the dates of the various events for each patients (e.g., surgery(ies), communication of surgery results, radio- and chemotherapy), which involved a complex fieldwork program and frequent contact with patients and interviewers. However, an advantage of these more complex logistics is the more frequent contact with respondents, which might have enhanced their commitment to the study. Lastly, a challenging aspect of the stage-linked design is the often short time period between different stages in the early period after diagnosis. Many women were not able (or willing) to fill out the questionnaire before first surgery or the post-surgery questionnaire before the start of adjuvant treatment. Unfortunately, this resulted in a lot of missings, which will be addressed in the subsequent paragraph.

The third and last unique feature of the FACT design is the reference group of women who were tested for breast cancer but who turned out to have no tumour or a benign tumour that did not need to be surgically removed. Not many studies included a reference group that allows for conclusions about the specific impact of cancer on psychological well-being. The comparison of the levels of distress, anxiety and non-specific distress in women with breast cancer to those in women in the reference group, enabled us to draw conclusions about the impact of various stages in the illness trajectory with more certainty. The fact that the reference group in the current study was not sampled from the general population can be regarded both a strength as well as a limitation. A s*trength* is that, except for the breast cancer diagnosis, women in this reference group were very similar to patients, i.e., they came from a similar region and were asked to participate in the same study, at the same point in time, for the same reason. Furthermore, since the eventual diagnosis was unknown at first clinic visit, all women were informed about the study. For this reason, it was very convenient to not only follow patients but also women with favorable results over time. A *limitation* might be that women in the reference group were confronted with the possibility of breast cancer, which might have caused distress, as well as perhaps relief around diagnosis (Scaf-Klomp, Sanderman, Van de Wiel, Otter, & van den Heuvel, 1997). At a group level, the levels of depression, anxiety and non-specific distress were highest at the first assessment after the benign diagnosis, indicating that the suspicion of breast cancer did have a negative effect. Nevertheless, from the assessment 8 weeks after diagnosis on, well-being in women in the reference group was stable and comparable to levels in the general population, indicating that the group was suitable as a reference sample. It should be mentioned however that the reference group did report an increase in psychological problems at last assessment, which was hard to interpret.

The sample

Most chapters in this study are about subsets of the 242 women with breast cancer that were enrolled in the FACT study. To allow for conclusions about the total population of women with breast cancer, it is important to know if this sample is representative in terms of demographic, medical and psychological characteristics. The response rate was rather low, i.e., 33% was willing to participate and could be contacted in time after diagnosis. A low response rate does however not necessarily imply a lack of representativeness. The sample seems not to be biased with respect to demographics and medical characteristics, i.e., the 242 women included were comparable to the regional population of women with breast cancer regarding age, cancer stage and treatment prescribed. However, the sample might have been somewhat biased with respect to psychological well-being. Besides no interest and no time, a known reason for non-response was the perception that participation was too burdensome. So, possibly, the sample consisted of the least distressed patients. Even though we cannot rule out this possibility, our impression from the telephone conversations we had with women is that we might have missed the most as well as the least distressed women. The study seemed to appeal to women in de medium distress range, who were not too distressed to deal with the extra burden of the study, but also not too unaffected to recognize the study's relevance. If our impression is true, it would imply that the range in distress is restricted in the current study, which might have limited our chances of finding relations. Moreover, this restricted distress range might have influenced the distress trajectories, i.e., perhaps the group reporting no distress as well as the group with stable high levels are larger in the total population. However, as this is only an impression, it might be valuable if researchers would try to examine the determinants of participation in this type of studies in more detail.

Due to occasional missings (41% of patients), drop out (10%) or both (6%), not all chapters of this thesis report on the total number of 242 patients. To make best use of all available data, we did not exclude women with missings, which resulted in different sample sizes across and sometimes even within chapters, depending on the research questions. Like non-response, also occasional missings and drop out might have affected the representativeness of the samples used. 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. In each of the chapters we attempted to show how missings could have affected the results. Overall, these comparisons show that missings were not entirely random, especially not missings due to drop out. Women who missed assessments in later stages were somewhat more distressed at earlier assessments. Even though such differences at earlier assessments were often small, we do not know how large they were at the missed assessments and they might have affected our descriptive results on the course of negative emotions over the first year.

In sum, recruiting cancer patients for participation in a rather intensive longitudinal study is challenging, and so is keeping them in the study until the last assessment. The current study managed to include a large number of patients. Yet, like most longitudinal studies, we had to deal with missing data. Attempts were made to limit the number of missings as much as possible, for example by returning incomplete questionnaires to participants, or by allowing completion trough telephone or e-mail.

The instruments
The current study made use of both quantitative and qualitative methods of data collection. The questionnaires we used were mostly well-validated scales that are used often in health psychology research. Even though most findings are based on the questionnaires, the face-to-face interviews added valuable information and illustrative material. For example, we presented how women ranked the stressfulness of the various stages the illness trajectory in retrospect. Moreover, we made use of the insights the interview gave in how women felt they could exert control over cure. Furthermore, the more open-ended questions in the interview data were used to illustrate or confirm the findings based on the quantitative methods. In sum, we believe the combination of both methods of data collection gave us a more complete picture of the experiences of women with breast cancer.

The analyses
Throughout this thesis, we made use of some established analytical techniques. Yet, we also reported on more innovative methods. In Chapter 2, we applied an advanced technique of longitudinal data analysis, i.e. group-based trajectory modeling (Jones et al., 2001). When analyzing change over time, often researchers use a 'variable-centered' method (Laursen & Hoff, 2006), which results in an average trajectory for the group as a whole. Such a 'variable centered' method was applied in Chapter 3, where we compared the effect of various illness stages on three different indicators of negative effect. In contrast, a 'person-centered' analysis takes into account that individuals do not show the same pattern of change over time and aims to identify groups of respondents with similar patterns. Group-based trajectory modeling is such a 'person-centered' approach. This modeling technique identified four groups that each showed a different pattern of distress over time. We believe this approach resulted in more refined knowledge about individual differences in adjustment after a breast cancer diagnosis.

In Chapter 6, we applied multiple mediation analysis adopting a procedure suggested by Preacher and Hayes (2008). Mediators are variables that transmit the effect of an independent variable on a dependent variable (MacKinnon, Fairchild, & Fritz, 2007). In this study, we were interested in variables that transmit the effect of perceived personal control on psychological well-being in women with breast cancer. As the mediators we were investigating (threat appraisal, coping self-efficacy, active engagement in medial interaction and in social life) were overlapping, we examined their unique contribution by including them all-together in one model. The confidence intervals around both the overall indirect effect and the unique effect of each mediator were construed based on bootstrapping. We believe this technique provided more information on mediation than single mediation models would have done.

In sum, advances in methodological techniques provided us with the necessary tools to answer more refined questions about the adjustment to breast cancer in the first year. Even though sometimes tempting, advanced techniques should however never become a goal in their own right. We agree with Sampson & Laub (2005) that researchers should not 'be obsessed with tools rather than keeping their eye on the prize'.

9.4 Conclusions

This thesis provided new insights in the adjustment process after a breast cancer diagnosis and the role of a sense of personal control therein. It was shown that research on adjustment to cancer should take *differences between individuals* as well as *differences between various types of negative emotions* into account. First of all, women with breast cancer showed different patterns of adjustment after diagnosis. A large group of women did not report any distress; a similarly large group recovered after the active treatment phase; a small but substantial group reported a delayed increase in distress in the re-entry phase; a similarly sized group reported elevated distress in all stages after diagnosis. More research into the predictors of such patterns is needed. Second, it was shown that the various phases after a breast cancer diagnosis did not trigger anxiety, depressive symptoms and non-specific distress to the same degree. The initial response right after diagnosis was mostly characterized by anxiety, while later stages were mostly characterized by nonspecific distress. Depressive symptoms were hardly elevated in women with breast cancer. These results have implications for clinical practice. Third, it was demonstrated that short waiting periods before diagnosis and surgery do not have maladaptive overwhelming effects and might shorten stressful periods for women with breast cancer.

Besides adding insights in the course of psychological well-being of women after a breast cancer diagnosis, this thesis replicated the adaptive effect of a strong sense of control over life when facing cancer. The current study not only showed *that* a sense of control is adaptive, but also *why* that is so. The beneficial effect of a sense of control can be attributed to less threat appraisal, more coping self-efficacy and less disengagement from social life during treatment. Furthermore, it was shown that, despite the uncertain nature of cancer, women generally maintained their sense of control over life. This thesis not only added knowledge on the role of personal control over life, but also on the role of personal control over the cure of cancer. Women who believed in a personal influence on cure were shown to have a stress-resilient personality and were not more vulnerable to distress when confronted with disappointing news than women with low cancer-specific control perceptions. Finally, recognizing the importance of acceptance in uncontrollable circumstances, the validity of an instrument assessing accommodative and assimilative coping styles was tested. It was shown that these scales need improvement before they can be used in psycho-oncology research.

In sum, despite the considerable number of studies on psychological issues related to breast cancer, this thesis has shown that new insights can be gained by asking refined questions, by including mediators and moderators and by taking new approaches to examine longitudinal data. Even though women with breast cancer show remarkable resilience, the stressors in different stages after breast cancer can be taxing for some. Research in psycho-oncology can provide the knowledge necessary to detect, prevent and treat cancer-related distress.

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Summary

Since the mid-1970s, research in psycho-oncology has increased our understanding of psychological issues related to the diagnosis, treatment and survival of cancer. As, by now, we know much more about the impact of the disease on psychological well-being and about the various predictors of successful adjustment, researchers started to ask more and more refined questions. This thesis addressed several novel issues regarding the course of psychological well-being in the first year after a breast cancer diagnosis. In addition, the position of perceived personal control in the adjustment process was examined, with the aim to answer not only *if*, but also *when* and *why* a sense of control is beneficial. **Chapter 1** shortly describes the rise of psycho-oncology, provides some facts about breast cancer in the Netherlands, summarizes the various treatment protocols and introduces the two main topics of this thesis as well as the FACT (Feelings of control and Adjustment to Cancer and Treatment) study design.

Part 1. Psychological well-being after a breast cancer diagnosis

As a cancer diagnosis is threatening and can abruptly changes people's life, patients often experience negative emotions, like anxiety or sadness. Knowledge about the course of such emotions has implications for the practice of psycho-social screening as well as for the development of tailored psycho-social interventions. In the current study, the assessment of psychological well-being was linked to meaningful stages in the illness trajectory: (1) the period of suspicion, before diagnosis; (2) the period right after diagnosis, when treatment had not yet started; (3) the period after surgery, when pathology results and the adjuvant treatment plan were communicated; (4) the period right after the completion of radiotherapy and/or chemotherapy; (5) the re-entry phase, two months after the end of treatment and (6) the short-term survivorship phase six months after the end of treatment. A total of 242 women with breast cancer and 670 women without breast cancer were included in the study. Data collection involved paper questionnaires and interviews at patients' home.

Most studies that examined the course of negative emotions over the first year after diagnosis conclude that emotional well-being is most impaired in the first months and gradually improves thereafter. The findings reported in **Chapter 2** demonstrate this does not hold true for all patients. By applying a method of analysis that identifies groups of individuals with a similar patterns of change, four distinct trajectories of distress were found in women who were treated with adjuvant radio-and or chemotherapy. First of all, a fairly large group of women (*36%*) had no psychological problems after diagnosis. This finding supports the growing body of evidence that many people are able to adjust successfully to the stressors cancer brings. Furthermore, a similarly large group of women (*33%*) showed the pattern most often reported in studies examining the course of distress at a group level - high during the first months but recovering once treatment in the hospital is over. By contrast, a smaller, but still considerable number of women began to feel distressed in the re-entry phase (*15%*). Finally, there was a similar-sized group of patients experiencing chronically elevated levels of distress (*15%*). Demographic and objective medical characteristics could not significantly predict group membership; the number of complaints due to adjuvant treatment as well as mastery, neuroticism and optimism could. In a multivariate analysis, mastery was the only unique predictor. Compared to the other three groups, women who showed a no-distress trajectory after diagnosis reported the least physical complaints due to adjuvant treatment. Compared to the recovery and chronic trajectory group, they also had the strongest personal resources (high optimism and mastery, low neuroticism). Women reporting late distress could only be distinguished from the no-distress group by a higher number of complaints due to adjuvant treatment. Besides physical complaints, there might however be several other reasons for the emergence of psychological problems in the re-entry phase that need to be addressed in future research, e.g., a delayed psychological response to the hectic period of diagnosis and treatment, fear of recurrence or problems with getting back to life as usual. Women with chronic high scores on distress had higher scores on neuroticism than women who recover. Neuroticism is an often reported risk factor for psychological distress under ‘usual’ as well as under stressful circumstances. It remains unclear if the chronic high levels of distress were due to difficulties in adjusting to cancer or due to previous psychological problems, either triggered by or entirely unrelated to cancer.

Besides identifying individual trajectories in distress, this thesis examined if and how three indicators of emotional well-being are differentially affected by the various illness stages. Even though different types of negative emotions are often experienced simultaneously, they each have unique features and theory suggest they are triggered by different types of events. **Chapter 3** compares the levels of anxiety, depressive symptoms and non-specific distress in women treated with adjuvant radio- and/or chemotherapy to those in an age-matched reference group consisting of women who were diagnosed with no tumor or with a benign breast disease. The findings show that, even though correlations between depressive symptoms, anxiety and non-specific distress were strong, the various phases after a breast cancer diagnosis did not trigger these emotions to the same degree. The initial response right after diagnosis was mostly characterized by *anxiety*. Anxiety is thought to be provoked by the confrontation with imminent danger. At the first assessments, patients have just learned they have a serious disease that might involve important life changes on the short as well as on the long term. Anxiety decreased to normal in later phases. *Depressive symptoms*, on the other hand, were hardly elevated in women with breast cancer. Depression is thought to be the consequence of an experienced irrevocable loss and, related to that, of a sense of hopelessness. Possibly, women with newly diagnosed breast cancer who are treated with curative intent are not dealing with many or intense loss experiences that trigger depression. Lastly, *nonspecific distress* symptoms (i.e., general symptoms that indicate a discontinuity in normal functioning) were elevated in all stages, mostly right after surgery, and were only normalizing in the short-term survivorship stage. This result seems to indicate that, after the initial crisis period after diagnosis, the negative affect cancer patients experience might be of a more general kind.

Lastly, a specific predictor of psychological well-being was examined in **Chapter 4**, i.e., the length of waiting periods. Based on common sense, one might assume that sooner is always better. In line with this assumption, breast care clinics are nowadays evaluated based on the length of their waiting periods. However, considering that the beneficial effect of short waiting periods on the prognosis in breast cancer is modest, one could also argue that short waiting periods can have an overwhelming effect and do not give patients enough time to adjust and to prepare for what is coming. This suggestion was not supported by the data. The findings show that even though the period before diagnosis was considered stressful, the length of the waiting period *before diagnosis* did not affect post-diagnosis well-being of women diagnosed with breast cancer. A late definite diagnosis (longer than 2 weeks after first diagnostic tests) did affect post-diagnosis well-being of women who were eventually not diagnosed with breast cancer. These women were worried and distressed for a longer period of time than women who received the good news sooner. Apparently, the long diagnostic period raised concerns that did not easily vanish after good news was finally delivered. These results, together with the finding that breast cancer patients ranked the period before diagnosis as the most stressful, advocate a speedy diagnosis. The waiting period *before surgery* did not affect psychological well-being post-surgery, i.e., women who had surgery within two weeks after diagnosis were not worse or better off after surgery than women who had to wait for a longer period of time. However, the finding that patients' well-being considerably improved after surgery, seems to provide support for the benefits of a speedy surgery. Nevertheless, if medically allowed, the individual whishes of patients should be taken into account when planning treatment.

Part 2: Perceived personal control and psychological adjustment

The second theme of this thesis is the role of perceived personal control in the adjustment process. For decennia, researchers from different fields of psychology have theorized about the concept and importance of a sense of personal control. In this thesis, two types of personal control were addressed, i.e., a sense of control over life in general and over the illness itself.

Personal control over life in general, also referred to as mastery, 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. A sense of control over life not only *regulates* the impact of stress, but might also be *affected by* the stressful life event. We addressed this two-sided position of mastery in the stress process in **Chapter 5**, by making use of data collected in the Relationship and Adjustment to Cancer study (RAAK). We compared women without breast cancer (*no threat*) to women with breast cancer (*threat*) and women with breast cancer who were treated with chemotherapy (*most threat*). Only patients treated with chemotherapy, who face a longer treatment trajectory and relatively less good prognostic prospects, reported lower levels of personal control compared to women from the general population. The difference was largest at nine months after diagnosis, which was attributed to problems specific to the re-entry phase, like the loss of medical monitoring and the risk of recurrence. In addition, results provided modest support for the stress-buffering potential of control. Longitudinally, strong personal control shortly after diagnosis predicted a decrease in distress, yet only in patients treated with chemotherapy. Cross-sectionally, women treated with chemotherapy were shown to profit more from a strong sense of control over life than healthy women at nine months after diagnosis. Interestingly, it is also in this phase of the illness trajectory, just after the completion of treatment, that a sense of control was shown to be lowest in this group. It was concluded that personal control is a valuable but a threatened personal resource in this particular phase.

Even though numerous studies showed that a sense of control over life is adaptive when facing cancer, not many studies addressed the question ‘why?’. In **Chapter 6**, 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 on the *subsequent psychological adjustment*. In this study, we loosely adopted the stress coping framework of Lazarus and Folkman, which 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. The study made use of the prospective nature of FACT, which included a pre-diagnosis assessment. A strong sense of control over life before diagnosis predicted a less salient response in psychological distress after diagnosis. In line with our hypotheses, this protective effect of personal control was mediated by threat appraisal and coping self-efficacy. Women with a low sense of control appraised cancer and their personal coping skills more negatively, which made them vulnerable to distress after diagnosis. A strong sense of control over life also predicted lower levels of anxiety, yet not a decrease in distress in the re-entry phase. The adaptive effect of personal control on anxiety in the re-entry phase was mediated by threat appraisal and by active engagement in social life during treatment. Women with a strong sense of control regulated anxiety by appraising cancer less negatively and by remaining engaged in social life during treatment (meeting friends, not avoiding visits, paying attention to friends or family). These insights add to our theoretical understanding and might direct the development of psychological interventions offered to patients.

Besides a general sense of control over life, perceived personal control over the illness has shown to be related to adjustment to illness as well. There is however still debate about the direction of this relation. Cognitive adaptation theory suggests that personal control over the illness, even though illusionary to some degree, acts as a stress buffer when faced with a setback. So the more severe the illness, the more important a sense of control is. In contrast, other researchers argued that maladaptive outcomes occur when a sense of control is not in line with reality. A strong belief in personal control over uncontrollable illness aspects might prevent patients from mentally preparing for a disappointment and might provoke feelings of inadequacy and responsibility. Combining both lines of reasoning, Janoff-Bulman suggested that *general* beliefs about the self are adaptive at all times, while *specific* beliefs are vulnerable to disconfirmation. In **Chapter 7,** we tested these assumptions by examining if the adaptive effect of perceived control, both over life and over cure, depended on the news women received after surgery. News after surgery was considered to be disappointing when pathology results indicated that chemotherapy was necessary (i.e., when the tumor is larger, more aggressive or has spread to the lymph nodes). Results showed that disappointing news after surgery resulted in an increase in anxiety and threat appraisal. Yet, it did not moderate (enhance nor limit) the adaptiveness of personal control (over cure nor life). In conclusion, a strong belief in personal control over cure does not seem to have maladaptive effects. However, we can only draw conclusions about the first, curative phase of the illness.

There were various beliefs underlying a strong sense of personal control over the cure of breast cancer. In line with media portrayals of cancer experiences, many women believed that maintaining a positive attitude promotes cure. Next to a fighting spirit, accepting treatment and adopting a healthy life style were commonly mentioned. Women with a strong sense of control over cure were best characterized by high optimism and strong sense of control over life in general; characteristics that reflect stress-resilience. Yet, women with a strong sense of control over cure also had invasive cancer more often than women with low control perceptions, which could indicate a stronger situational induced need for control over cure.

Overall, the findings of this thesis support the notion that a strong sense of control is a valuable personal resource when diagnosed with breast cancer. However, successful adjustment might also involve acceptance and letting-go. The terms *assimilation* (‘holding on’) and *accommodation* (‘letting go’) originate from the dual-process theory of self-regulation and can be assessed with the Tenacious Goal Pursuit (TGP) and the Flexible Goal Adjustment (FGA) scales. TGP implies the tendency to tenaciously pursue goals even in the face of obstacles; FGA reflects the tendency to positively reinterpret initially aversive situations and to relinquish blocked goal perspectives easily. As people’s general tendency to use such assimilative and accommodative coping strategies might affect adjustment after a breast cancer diagnosis, the scales were included in the FACT study. **Chapter 8** addresses the validity of the scales in the reference sample of women who were not diagnosed with cancer. First of all, *factorial* validity was not supported. In line with earlier findings, the direction in which the items were formulated (direct or reverse) explained the same amount of variance in items scores as coping content. Second, and related, *convergent* nor *divergent* validity was not supported, i.e. groups of items with similar coping content correlated just as strongly as groups of items that were similarly keyed. Third, *face validity* of particularly the reverse coded items appeared to be weak. In our opinion, this lack of validity has it's origins not in item construction, but in concept definition. The definitions of FGA and TGP might be improved by including goal attainability, i.e. is a person pursuing or giving up on a goal that is just difficult or that is completely out of reach. Moreover, the difference between reaching a person-environment fit by either trying to change the circumstances or by adjusting one's personal preferences should be stressed more clearly. Based on these findings, we gave some suggestions for a revision of the definitions as well as the instrument.

Finally, **Chapter 9** of this thesis discusses the main findings of this thesis -*What's new?*-; provides suggestions for future research and clinical practice -*So (now) what?*- and reflected on strengths and weaknesses of the study. The current study added to the numerous studies on adjustment to breast cancer by examining the course of psychological well-being over illness-related stages in the first year, taking into account individual differences in patterns of change and comparing various indicators of psychological well-being. Moreover, knowledge on the role of personal control in the adjustment process has been extended by examining both mediators and moderators of the relation between control and well-being.

Samenvatting

Sinds de opkomst van de psychosociale oncologie midden jaren 70 is onze kennis over psychische aspecten gerelateerd aan de diagnose, behandeling en overleving van kanker sterk toegenomen. Aangezien we nu veel meer weten over de impact van de ziekte op het emotioneel welbevinden van patiënten en over de voorspellers van succesvolle psychologische aanpassing, richten onderzoekers zich op steeds specifiekere vragen. Dit proefschrift belicht het verloop van het emotioneel welbevinden in het eerste jaar na de diagnose borstkanker vanuit een nieuwe invalshoek. Daarnaast beschrijft het de rol van waargenomen controle in het aanpassingsproces, waarbij niet alleen wordt nagegaan *óf* waargenomen controle gunstig is, maar ook *wanneer* en *waarom* dat zo is. **Hoofdstuk 1** staat kort stil bij de intrede van de psychosociale oncologie, presenteert gegevens over borstkanker in Nederland, vat de verschillende behandelingsprotocollen samen en introduceert de twee hoofdonderwerpen van het proefschrift en het design van het FACT onderzoek (Feelings of control and Adjustment to Cancer and Treatment).

Deel 1. Emotioneel welbevinden na de diagnose borstkanker

De diagnose kanker is stressvol en kan het leven ingrijpend veranderen. Patiënten ervaren dan ook vaak negatieve emoties, zoals angst of somberheid. Wetenschappelijk onderzoek naar het verloop van dergelijke emoties kan richting geven aan de zorg voor patiënten in de klinische praktijk, onder andere wat betreft de timing van psychosociale screening en de ontwikkeling van psychosociale interventies op maat. In het huidige onderzoek werd het emotioneel welbevinden van vrouwen met borstkanker in betekenisvolle fases van het ziektetraject gemeten: (1) in de fase van verdenking, voor de diagnose; (2) in de fase net na diagnose, voor de start van de behandeling; (3) in de fase net na de operatie(s), wanneer de pathologie-uitslagen en het behandelplan zijn gecommuniceerd; (4) in de fase net na de afronding van radio- en/of chemotherapie (adjuvante therapie); (5) in de herintredingsfase, twee maanden na afronding van de adjuvante behandeling; (6) in de korte termijn overlevingsfase, zes maanden na afronding van de behandeling. In totaal deden 242 vrouwen mét en 670 vrouwen zónder borstkanker mee aan het onderzoek. De gegevens werden verzameld middels vragenlijsten en interviews bij patiënten thuis.

De meeste studies gericht op het verloop van negatieve emoties in het eerste jaar na diagnose concluderen dat het emotioneel welbevinden van patiënten vooral is aangetast in de eerste maanden na diagnose en dat het zich daarna langzaam herstelt. De bevindingen in **Hoofdstuk 2** laten zien dat dit niet voor alle patiënten geldt. Door gebruik te maken van een analysemethode die groepen met een zelfde veranderingspatroon identificeert, werden vier verschillende trajecten in psychische klachten gevonden onder vrouwen die behandeld zijn met radio- en/of chemotherapie. Een vrij grote groep vrouwen (36%) rapporteerde op geen enkel moment psychische klachten na diagnose. Dit resultaat ondersteunt het groeiende besef dat veel mensen in staat zijn zich succesvol aan te passen aan de stressoren die kanker met zich mee brengt. Daarnaast vertoonde een eveneens grote groep (*33%*) het patroon dat veelal wordt gerapporteerd in studies die het verloop van psychische klachten op groepsniveau onderzoeken - veel klachten in de eerste maanden, maar herstel na afronding van de behandeling in het ziekenhuis. Een kleinere, maar nog altijd aanzienlijke groep vrouwen (*15%*) begon daarentegen pas klachten te rapporteren in de zogenaamde herintredingsfase, na afronding van de behandeling. Ten slotte bestond er een even grote groep (*15%*) die chronisch psychische klachten rapporteerde, in alle fases van het ziektetraject. Demografische en objectieve medische kenmerken konden de trajecten in psychische klachten niet voorspellen. Het aantal fysieke klachten als gevolg van de adjuvante behandeling evenals waargenomen controle, optimisme en neuroticisme waren wel significante determinanten. In multivariate analyses bleek waargenomen controle de enige unieke voorspeller. In vergelijking met de drie andere groepen rapporteerden vrouwen die op geen moment psychische problemen hadden de minste fysieke klachten als gevolg van de adjuvante behandeling. In vergelijking met de groep die herstelt en de groep die chronisch klachten rapporteert, beschikten zij tevens over persoonlijkheidskenmerken die op weerbaarheid duiden (sterk optimistisch, sterk gevoel van controle, laag op neuroticisme). Vrouwen die pas later in het traject problemen gingen ondervinden, konden enkel worden onderscheiden van vrouwen die op geen enkel moment problemen hadden door een hoger aantal fysieke klachten als gevolg van de adjuvante behandeling. Naast zulke fysieke klachten, kunnen er echter andere redenen zijn voor het late ontstaan van psychische klachten, zoals een verlate verwerkingsreactie op de hectische periode in het ziekenhuis, angst voor terugkeer van kanker en problemen met het oppakken van het leven. Deze aspecten verdienen aandacht in toekomstig onderzoek. Verder bleek dat vrouwen die in alle fases problemen rapporteerden alleen verschilden van vrouwen die zich na de behandeling herstelden door een hogere score op neuroticisme. Neuroticisme is een bekende risicofactor voor psychische problemen, zowel onder gebruikelijke als onder stressvolle omstandigheden. Het is onduidelijk of de chronische klachten in deze groep werden veroorzaakt door moeilijkheden in de aanpassing aan kanker of dat ze al bestaande psychische problemen reflecteren, die wellicht door de kanker werden getriggerd of misschien zelfs niets te maken hadden met de ziekte.

Naast het identificeren van verschillende veranderingspatronen in psychische klachten, beschrijft dit proefschrift ook hoe drie indicatoren van emotioneel welbevinden werden beïnvloed door de verschillende fases in het ziektetraject. Ook al worden verschillende negatieve emoties vaak tegelijkertijd ervaren, ze hebben elk verschillende kenmerken. Ook veronderstellen emotietheorieën dat ze door verschillende soorten gebeurtenissen worden opgeroepen. **Hoofdstuk 3** vergelijkt vrouwen die behandeld zijn met radio- en/of chemotherapie met een op leeftijd gematchte vergelijkingsgroep van vrouwen die wel de mammapoli bezochten, maar geen borstkanker bleken te hebben, ten aanzien van niveaus van angst, depressieve symptomen en aspecifieke psychische klachten. De resultaten laten zien dat, hoewel de drie indicatoren sterk gecorreleerd zijn, de verschillende fases na diagnose de emoties niet in dezelfde mate teweegbrachten. De eerste reactie na diagnose werd voornamelijk gekenmerkt door *angst*. Angst is over het algemeen een emotionele reactie op dreigend gevaar. In de eerste fases hebben patiënten net gehoord dat ze een ernstige ziekte hebben die mogelijk belangrijke levensveranderingen op de korte en lange termijn tot gevolg kan hebben. *Depressieve symptomen*, daarentegen, waren nauwelijks verhoogd onder vrouwen met borstkanker. Depressie is over het algemeen een reactie op een onomkeerbaar verlieservaring en - daarmee samenhangend – op een gevoel van hulpeloosheid. Mogelijk worden vrouwen met borstkanker die curatief behandeld worden niet geconfronteerd met veel of intense verlieservaringen die depressieve gevoelens uitlokken. Ten slotte, *aspecifieke psychische klachten* (algemene symptomen die wijzen op een verstoring van het normale functioneren) waren verhoogd in alle fases na diagnose en normaliseerden pas in de korte termijn overlevingsfase. Deze bevindingen lijken erop te wijzen dat, na de initiële crisisperiode volgend op de diagnose, het negatieve affect van borstkankerpatiënten vooral van een aspecifieke aard is.

Ten slotte werd in **Hoofdstuk 4** een specifieke voorspeller van emotioneel welbevinden onderzocht, namelijk de lengte van wachttijden. Op basis van gezond verstand zou men verwachten dat sneller altijd beter is. In overeenstemming met deze gedachte worden mammapoli's tegenwoordig geëvalueerd op basis van hun wachttijden. Echter, aangezien de gunstige invloed van korte wachttijden voor de prognose bij borstkanker bescheiden is, zou men ook kunnen beredeneren dat korte wachttijden mogelijk een overrompelend effect hebben en patiënten niet de tijd geven om zich aan te passen en voor te bereiden op wat komen gaat. Deze veronderstelling werd niet ondersteund door de data. De resultaten lieten zien dat, hoewel de periode voor diagnose wel als stressvol werd ervaren, de wachttijd tot definitieve diagnose niet van invloed was op het emotioneel welbevinden na de diagnose borstkanker. Een diagnose die lang op zich liet wachten (> 2 weken) was wel van invloed op het welbevinden van vrouwen die geen borstkanker bleken te hebben. Deze vrouwen waren langer bezorgd en bleven langer klachten rapporteren dan vrouwen die het goede nieuws sneller kregen. Blijkbaar zorgde de lange diagnostische periode voor zorgen die niet gemakkelijk weer verdwenen nadat het goede nieuws er eindelijk was. Deze resultaten, samen met de bevinding dat vrouwen achteraf de periode vóór diagnose het meest stressvol vonden, pleiten voor snelle diagnostiek. De wachttijd tot operatie was niet van invloed op het welbevinden daarna. Vrouwen die binnen twee weken werden geopereerd, waren niet beter of slechter af na operatie dan vrouwen die langer moesten wachten. Echter, het feit dat het welbevinden van vrouwen aanzienlijk verbeterde na operatie, lijkt te pleiten voor een snelle operatie. Niettemin zouden, indien medisch toelaatbaar, de voorkeuren van de individuele patiënt een rol moeten spelen in de tijdsplanning van de behandeling.

Deel 2. Waargenomen controle en psychologische aanpassing

Het tweede thema van dit proefschrift is de rol van waargenomen persoonlijke controle in het aanpassingsproces. Al decennia lang schrijven onderzoekers uit verschillende psychologische disciplines over het concept en het belang van een gevoel van persoonlijke controle. In dit proefschrift gaat het over twee soorten controle, namelijk het gevoel zelf invloed te hebben op het leven in het algemeen en over het gevoel persoonlijk invloed te hebben op de ziekte zelf.

Waargenomen controle over het leven in het algemeen, ook wel mastery genoemd, is het geloof dat het leven niet bepaald wordt door het lot, maar dat men zelf in staat is belangrijke uitkomsten en situaties in het leven te beïnvloeden. Een gevoel van controle *reguleert* niet alleen de impact van een stressvolle gebeurtenis, maar kan zelf ook *worden beïnvloed* door de stressvolle situatie. Deze tweezijdige positie van mastery in het stress proces werd onderzocht in **Hoofdstuk 5**, waarbij we gebruikmaakten van de data verzameld in het 'Relatie en AAnpassing aan Kanker' onderzoek (RAAK). We vergeleken vrouwen zonder borstkanker (*geen dreiging*) met vrouwen met borstkanker (*dreiging*) en met vrouwen met borstkanker die behandeld werden met chemotherapie (*meeste dreiging*). Alleen vrouwen die behandeld werden met chemotherapie - die een langer behandelingstraject doorliepen en een relatief minder goede prognose hadden - bleken een lager gevoel van controle te rapporteren in vergelijking met vrouwen uit de algemene populatie. Dit verschil was het grootst negen maanden na diagnose, wat werd toegeschreven aan problemen specifiek voor de herintredingsfase, zoals het wegvallen van medisch toezicht en het risico op terugkeer van de kanker. Daarnaast boden de resultaten enige ondersteuning voor de stressbufferende werking van waargenomen controle. Longitudinaal voorspelde een sterk gevoel van controle kort na diagnose een afname in psychische klachten in de maanden daarop, maar alleen voor vrouwen die chemotherapie ondergingen. Cross-sectionele resultaten lieten zien dat controle over het leven belangrijker was voor het welbevinden van vrouwen die behandeld werden met chemotherapie dan voor gezonde vrouwen negen maanden na diagnose. Juist in deze fase van het ziektetraject, na afronding van de behandeling, bleek het gevoel van controle het laagst in deze groep. Het hoofdstuk concludeert dan ook dat waargenomen controle een waardevol maar bedreigde persoonlijke hulpbron is in deze periode.

Ook al lieten veel studies zien *dát* een gevoel van controle adaptief is wanneer men wordt geconfronteerd met kanker, niet veel onderzoek richtte zich op de vraag '*waarom?*'. In **Hoofdstuk 6** onderzochten we of kankerspecifieke *cognitieve appraisal* (inschattings-) processen en twee vormen van *actief gedrag* het effect van waargenomen controle op de *initiële response* in psychische klachten en de daaropvolgende *psychologische aanpassing* konden verklaren. Deze studie was deels gebaseerd op de stress-coping theorie van Lazarus en Folkman, die veronderstelt dat de reactie op stress afhankelijk is van de inschatting die de persoon van de situatie maakt en van de wijze waarop de persoon met de situatie omgaat. Het onderzoek maakte gebruik van het prospectieve karakter van FACT studie met een meting vóór diagnose. Vrouwen met een sterk gevoel van controle vóór de diagnose borstkanker rapporteerden een minder sterke toename in psychische klachten ná de diagnose dan vrouwen met een laag gevoel van controle. Overeenkomstig onze verwachtingen, bleek dat dit beschermende effect van waargenomen controle werd gemedieerd (verklaard) door kankerspecifieke inschattingsprocessen. Vrouwen met een laag gevoel van controle schatten de situatie en hun eigen vaardigheden om met de ziekte om te gaan negatief in, waardoor zij meer psychische klachten hadden na diagnose. Een sterk gevoel van controle kon ook een afname in angst in latere fases voorspellen, maar niet een afname in algemene psychische klachten. Het gunstige effect van waargenomen controle op angst na de behandeling werd gemedieerd door wederom de inschatting die vrouwen maakten van de dreiging in de situatie, maar ook door de mate waarin zij actief sociaal betrokken bleven gedurende de behandeling. Vrouwen met een sterk gevoel van controle konden hun angst reguleren doordat zij de situatie als minder bedreigend inschatten en meer betrokken bleven bij hun sociale leven (vrienden ontmoetten, bezoek niet vermeden, aandacht hadden voor familie en vrienden). Deze inzichten vergroten onze theoretische kennis en kunnen richting geven aan de ontwikkeling van psychosociale ondersteuning voor kankerpatiënten.

Onderzoek laat zien dat niet alleen een algemeen gevoel van controle over het leven, maar ook waargenomen controle over de ziekte gerelateerd is aan psychologische aanpassing. Over de richting van deze samenhang zijn de meningen echter nog verdeeld. De cognitieve adaptatie theorie stelt dat persoonlijke controle over de ziekte, ook al is die niet geheel realistisch, stressbufferend kan werken wanneer patiënten met tegenslag worden geconfronteerd. Dus, hoe ernstiger de ziekte, hoe belangrijker een gevoel van controle. Andere onderzoekers concluderen daarentegen dat een gevoel van controle dat niet klopt met de realiteit nadelige gevolgen kan hebben. Een sterk gevoel van controle over oncontroleerbare aspecten van de ziekte maakt wellicht dat patiënten zich niet mentaal op een tegenslag voorbereiden en zou kunnen leiden tot een gevoel van verantwoordelijkheid of zelfverwijt. Janoff-Bulman combineert beide invalshoeken en stelt dat *algemene* opvattingen over jezelf en je rol in de wereld altijd adaptief zijn, terwijl meer *specifieke* opvattingen gemakkelijker ontkracht worden. In **Hoofdstuk 7** hebben we deze assumpties getoetst door te onderzoeken of het adaptieve effect van een gevoel van controle, zowel over het leven als over de genezing van de ziekte, afhankelijk is van het nieuws dat vrouwen krijgen na de operatie. De boodschap dat chemotherapie noodzakelijk was (wanneer de tumor groot, agressief of uitgezaaid is) werd beschouwd als teleurstellend nieuws. De resultaten lieten zien dat angst en de ingeschatte dreiging toenamen na teleurstellend nieuws. Echter, teleurstellend nieuws na operatie modereerde (vergrootte noch verkleinde) het adaptieve effect van waargenomen controle (over het leven en over de genezing) niet. Dus, een sterk gevoel van persoonlijke controle over de genezing van borstkanker lijkt geen negatieve gevolgen te hebben, al kunnen we alleen uitspraken doen over de eerste, curatieve fase van de ziekte.

Er bleken verschillende ideeën ten grondslag te liggen aan een gevoel van controle over de genezing van borstkanker. In overeenstemming met verhalen over kanker in de media, hadden veel vrouwen het idee dat het behouden van een positieve instelling de genezing zou bevorderen. Naast vechtlust, werd het accepteren van de behandeling en het aannemen van een gezonde levensstijl vaak genoemd. Vrouwen met een sterk gevoel van persoonlijke controle over de genezing van borstkanker werden vooral gekenmerkt door hun optimisme en een sterk gevoel van controle over het leven in het algemeen – kenmerken die een weerbare persoonlijkheid reflecteren. Maar vrouwen met een sterk gevoel van controle over de genezing hadden ook vaker invasieve kanker (dus minder vaak kanker *in situ*), wat kan duiden op een sterkere behoefte aan controle ingegeven door de situatie.

De bevindingen in dit proefschrift laten zien dat waargenomen persoonlijke controle een waardevolle persoonlijke hulpbron is na de diagnose borstkanker. Toch omvat succesvolle aanpassing misschien ook acceptatie en loslaten. De concepten *assimilatie* (vasthouden) en *accommodatie* (loslaten) komen voort uit de ‘dual-process theory of self-regulation’ en kunnen worden gemeten met de ‘Tenacious Goal Pursuit (TGP)’ en de ‘Flexible Goal Adjustment (FGA)’ schalen. TGP is de neiging om vasthoudend doelen na te streven, zelfs onder lastige omstandigheden; FGA is de neiging om negatieve situaties positief te herinterpreteren en om onhaalbare doelen gemakkelijk los te laten. Aangezien de neiging om assimilatieve of juist accommodatieve coping strategieën te gebruiken, invloed kan hebben op de psychologische aanpassing na de diagnose borstkanker, zijn beide schalen meegenomen in het FACT onderzoek. **Hoofdstuk 8** test de validiteit van de schalen in de referentiegroep van vrouwen die geen borstkanker bleken te hebben. Allereerst werd de *factor* validiteit niet bevestigd. Net zoals in eerder onderzoek bepaalde de richting waarin de items waren geformuleerd (direct of omgekeerd) evenveel variantie in de scores als de copingstijl die de items beoogden te meten. Ten tweede, de *convergente* en *divergente* validiteit werd niet ondersteund. Sets van items die dezelfde copingstijl beoogden te meten correleerden net zo sterk als sets van items die in dezelfde richting waren geformuleerd. Ten derde, de *face* validiteit (of de items meten wat ze zouden moeten meten) van vooral de omgekeerd geformuleerde items was zwak. Naar onze mening heeft deze gebrekkige validiteit zijn oorsprong niet alleen in de constructie van de items, maar ook in de definities van de concepten. De definities van TGP en FGA kunnen wellicht worden verhelderd door de haalbaarheid van het doel erin te betrekken. Is het doel dat men nastreeft of juist opgeeft onhaalbaar of gewoon lastig? Daarnaast zouden de twee verschillende benaderingen om een ‘persoon-omgeving fit’ te bereiken moeten worden benadrukt. Wil men die fit bereiken door de omstandigheden te veranderen (TGP) of door de eigen voorkeuren aan te passen (FGA)? Op basis van de bevindingen gaven we een aantal suggesties voor een herziening van de definities en van het instrument.

Ten slotte bespreekt **Hoofdstuk 9** van dit proefschrift de centrale bevindingen - '*What's new?'* -; het geeft een aantal suggesties voor zowel toekomstig onderzoek als de klinische praktijk - *'So (now) what?'* - en het behandelt de sterke en zwakke punten van de studie. Het gepresenteerde onderzoek heeft een bijdrage geleverd aan de al bestaande literatuur over aanpassing aan borstkanker door het verloop van emotioneel welbevinden over betekenisvolle fases in het eerste jaar na diagnose te onderzoeken, waarbij rekening werd gehouden met individuele verschillen in veranderingspatronen en waarbij verschillende indicatoren van welbevinden werden vergeleken. Daarnaast biedt het onderzoek nieuwe inzichten in de rol van waargenomen controle in het aanpassingsproces door zowel oog te hebben voor mediatoren als voor moderatoren van de relatie tussen controle en welbevinden.

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Curriculum Vitae

Inge Henselmans werd geboren op 4 februari 1980 en ging in Kaatsheuvel naar basisschool De Touwladder. In 1998 behaalde ze haar VWO diploma aan het Dr. Mollercollege in Waalwijk en ging ze Psychologie studeren aan de Rijksuniversiteit Groningen. In 2003 studeerde ze cum laude af in de Sociale Psychologie en de nevenrichtingen Gezondheids- en Klinische Psychologie. Na haar afstuderen onderzocht Inge bij het Centre for Quality of Care Research van het UMC St. Radboud in Nijmegen de voorkeuren van rokers ten aanzien van ondersteuning bij het stoppen met roken. Ze volgde tevens een cursus wetenschapsjournalistiek. In 2004 deed ze bij GINO Software in Groningen onderzoek naar cliëntprofielen binnen de AWBZ indicatiestelling. In december van dat jaar startte ze met haar promotieonderzoek bij de sectie Health Psychology van het UMCG. Het onderzoek werd gesubsidieerd door KWF Kankerbestrijding en resulteerde in dit proefschrift. Inge volgde in deze periode diverse cursussen, o.a. op het gebied van projectmanagement, statistiek en oncologie. Ze presenteerde haar onderzoek op internationale congressen en bracht 3 maanden aan de Carnegie Mellon University in Pittsburgh door. Tevens gaf ze psychologieonderwijs aan Geneeskunde studenten. Eind 2009 start Inge met een vierjarig KWF fellowship voor sociaal oncologisch onderzoek op de afdeling Medische Psychologie van het Academisch Medisch Centrum in Amsterdam. Ze zal onderzoek doen naar de ondersteuning van kankerpatiënten in de communicatie met artsen.

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