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

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,
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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 (gold 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 at 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 lifestyle 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 and 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
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...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.,
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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 strength 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 the 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 through telephone or e-mail.
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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
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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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