Psychological well-being and perceived control after a breast cancer diagnosis
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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
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began to feel distressed in the re-entry phase (15%). Finally, there was a similarly 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 wishes 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
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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
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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.