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

Henselmans, Inge
Chapter 3

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

Submitted

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Chapter 3

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.
Chapter 3

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,
Anxiety, depression and distress after a breast cancer diagnosis

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

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Patients</th>
<th>Reference group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age M(SD; range)</td>
<td>55.0 (9.1; 31-74)</td>
<td>54.1 (8.4; 30-74)</td>
</tr>
<tr>
<td>Education %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>43%</td>
<td>47%</td>
</tr>
<tr>
<td>Intermediate</td>
<td>34%</td>
<td>28%</td>
</tr>
<tr>
<td>High</td>
<td>23%</td>
<td>25%</td>
</tr>
<tr>
<td>Children %</td>
<td>88%</td>
<td>84%</td>
</tr>
<tr>
<td>Children under 18 %</td>
<td>27%</td>
<td>22%</td>
</tr>
<tr>
<td>Paying job %</td>
<td>48%</td>
<td>53%</td>
</tr>
<tr>
<td>Partner %</td>
<td>88%</td>
<td>81%</td>
</tr>
</tbody>
</table>

Medical characteristics

<table>
<thead>
<tr>
<th>Stage %</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>6%</td>
</tr>
<tr>
<td>1</td>
<td>38%</td>
</tr>
<tr>
<td>2</td>
<td>45%</td>
</tr>
<tr>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Positive nodes %</td>
<td>39%</td>
</tr>
<tr>
<td>Mastectomy %</td>
<td>23%</td>
</tr>
<tr>
<td>More than 1 surgery %</td>
<td>37%</td>
</tr>
<tr>
<td>Adjuvant treatment RT/CT %</td>
<td></td>
</tr>
<tr>
<td>RT</td>
<td>49%</td>
</tr>
<tr>
<td>CT</td>
<td>13%</td>
</tr>
<tr>
<td>RT &amp; CT</td>
<td>38%</td>
</tr>
</tbody>
</table>
Chapter 3

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

<table>
<thead>
<tr>
<th></th>
<th>Patient group</th>
<th>Reference group</th>
<th>Differences*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Complete cases</td>
<td>Incomplete cases</td>
<td>Total cases</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) N</td>
<td>Mean (SD) N</td>
<td>Mean (SD) N</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>13.5 (3.6) 102</td>
<td>13.6 (3.9) 44</td>
<td>13.5 (3.7) 146</td>
</tr>
<tr>
<td>T2</td>
<td>11.5 (3.3) 102</td>
<td>11.9 (3.9) 69</td>
<td>11.7 (3.6) 171</td>
</tr>
<tr>
<td>T3</td>
<td>10.7 (3.2) 102</td>
<td>10.9 (3.5) 74</td>
<td>10.8 (3.3) 176</td>
</tr>
<tr>
<td>T4</td>
<td>10.6 (3.5) 102</td>
<td>11.0 (3.2) 75</td>
<td>10.8 (3.4) 177</td>
</tr>
<tr>
<td>T5</td>
<td>10.1 (3.0) 102</td>
<td>10.6 (2.8) 68</td>
<td>10.3 (2.9) 170</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>13.9 (8.0) 103</td>
<td>13.1 (10.6) 44</td>
<td>13.7 (8.9) 147</td>
</tr>
<tr>
<td>T2</td>
<td>10.7 (7.5) 103</td>
<td>12.5 (9.2) 68</td>
<td>11.4 (8.2) 171</td>
</tr>
<tr>
<td>T3</td>
<td>11.8 (8.9) 103</td>
<td>11.9 (8.7) 73</td>
<td>11.8 (8.8) 176</td>
</tr>
<tr>
<td>T4</td>
<td>10.3 (9.3) 103</td>
<td>10.5 (7.9) 74</td>
<td>10.4 (8.7) 177</td>
</tr>
<tr>
<td>T5</td>
<td>8.8 (8.6) 103</td>
<td>10.3 (7.9) 67</td>
<td>9.4 (8.3) 170</td>
</tr>
<tr>
<td>Distress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>3.2 (3.1) 98</td>
<td>3.5 (3.2) 46</td>
<td>3.3 (3.1) 144</td>
</tr>
<tr>
<td>T2</td>
<td>3.4 (3.1) 98</td>
<td>4.1 (3.6) 72</td>
<td>3.7 (3.4) 170</td>
</tr>
<tr>
<td>T3</td>
<td>3.1 (3.2) 98</td>
<td>3.9 (3.6) 78</td>
<td>3.5 (3.4) 176</td>
</tr>
<tr>
<td>T4</td>
<td>2.7 (3.6) 98</td>
<td>2.5 (3.2) 79</td>
<td>2.6 (3.4) 177</td>
</tr>
<tr>
<td>T5</td>
<td>2.2 (3.5) 98</td>
<td>2.0 (3.1) 70</td>
<td>2.1 (3.3) 168</td>
</tr>
</tbody>
</table>

* Difference between total reference group and total patient group at each assessment.
Chapter 3

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 × diagnosis) was different in patients compared to the reference group, $F_{\text{anxiety}}(3,257)= 29.2, p < .001$, $F_{\text{depression}}(3,256) = 3.4, p = .02$, $F_{\text{distress}}(3,256) = 6.9, p < .001$. 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%).
Chapter 3

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.
Reference List


Chapter 3


