Chapter 4

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

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Summary

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

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

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

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

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

<table>
<thead>
<tr>
<th>Chapter 4</th>
<th>T1-T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original design</td>
<td>T1-T3</td>
<td>T5</td>
</tr>
</tbody>
</table>
4.1 Introduction

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

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

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

4.2 Methods

Sample and design

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

3093 women informed

1226 women consented

1094 women met criteria

912 women reached and consented after diagnosis

670 women with no malignancy

242 women with malignancy

515 women with no malignancy

149 women with malignancy

432 women with no malignancy

96 women with malignancy

139 women with malignancy

202 women with malignancy

Research question 1 (complaints and worries before diagnosis)

Research question 2 (diagnostic speed)

Research question 3 (waiting for surgery)

Research question 4 (illness trajectory in retrospect)
Figure 4.2 Time line with the questionnaires completed at each assessment.

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

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

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

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

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

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

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

Analyses

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

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

4.3 Results

Psychological complaints and worries before diagnosis

Before diagnosis, women reported on average 2.5 out of the 12 possible psychological complaints, independent of the eventual diagnosis (Table 4.1). A total of 45% scored above the cut-off for psychological problems (versus 26% in
Before diagnosis, over a quarter of the women were often or almost always worried about their chances of having breast cancer. Women who were eventually diagnosed with a malignancy, reported more worries already before diagnosis (small effect, d = 0.25). For most women, these worries had little effect on their mood or daily activities.

**Effect of diagnostic speed**

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

**Effect of the waiting period before surgery**

After surgery, general psychological complaints did not change, while anxiety
The sooner, the better?

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

<table>
<thead>
<tr>
<th>Malignancy</th>
<th>Before diagnosis</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1</td>
<td>T2</td>
</tr>
<tr>
<td>Psychological complaints (0-12), M (SD)(^b)</td>
<td>2.3 (3.1)</td>
<td>3.5 (3.4)</td>
</tr>
<tr>
<td>Same day</td>
<td>2.4 (3.3)</td>
<td>3.5 (3.5)</td>
</tr>
<tr>
<td>&lt;= 2 weeks</td>
<td>2.4 (3.1)</td>
<td>3.5 (3.5)</td>
</tr>
<tr>
<td>&gt; 2 weeks</td>
<td>1.6 (2.2)</td>
<td>3.3 (2.8)</td>
</tr>
<tr>
<td>No malignancy</td>
<td>2.5 (3.2)</td>
<td>2.1 (3.1)</td>
</tr>
<tr>
<td>Psychological complaints (0-12), M (SD)(^c)</td>
<td>2.1 (3.0)</td>
<td>1.9 (2.8)</td>
</tr>
<tr>
<td>Same day</td>
<td>2.5 (3.2)</td>
<td>2.0 (3.0)</td>
</tr>
<tr>
<td>&lt;= 2 weeks</td>
<td>2.1 (3.0)</td>
<td>1.9 (2.8)</td>
</tr>
<tr>
<td>&gt; 2 weeks</td>
<td>2.5 (3.8)</td>
<td>3.5 (3.1)</td>
</tr>
<tr>
<td>Worries chance cancer (3-12), M (SD)(^d)</td>
<td>5.2 (1.8)</td>
<td>4.6 (1.8)</td>
</tr>
<tr>
<td>Same day</td>
<td>5.2 (1.9)</td>
<td>4.4 (1.7)</td>
</tr>
<tr>
<td>&lt;= 2 weeks</td>
<td>5.1 (1.6)</td>
<td>5.0 (1.8)</td>
</tr>
<tr>
<td>&gt; 2 weeks</td>
<td>5.1 (1.9)</td>
<td>5.6 (2.4)</td>
</tr>
</tbody>
</table>

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

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

The illness trajectory in retrospect

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

4.4 Discussion

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

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

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

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

<table>
<thead>
<tr>
<th></th>
<th>Before surgery T2</th>
<th>After surgery T3</th>
<th>n</th>
</tr>
</thead>
</table>
| Psychological complaints (0-12), M(SD)
  <=2 weeks                | 2.9 (2.7)         | 3.5 (2.8)        | 43 |
  2-3 weeks                | 3.5 (3.5)         | 3.1 (3.3)        | 48 |
  > 3 weeks                | 3.6 (3.5)         | 3.4 (3.5)        | 48 |
| Anxiety (7-28), M(SD)
  <=2 weeks                | 15.2 (4.5)        | 12.7 (3.7)       | 43 |
  2-3 weeks                | 15.9 (4.8)        | 13.5 (4.6)       | 48 |
  > 3 weeks                | 15.0 (4.4)        | 13.0 (3.9)       | 48 |
| Depressive symptoms (0-60), M(SD)
  <=2 weeks                | 13.1 (9.4)        | 10.7 (7.7)       | 43 |
  2-3 weeks                | 14.3 (9.9)        | 10.9 (9.5)       | 48 |
  > 3 weeks                | 14.3 (9.3)        | 11.4 (8.3)       | 48 |

a Groups did not differ at T2; b Ftime x waiting period (2,136) = 1.570, p = .21; c Ftime x waiting period (2,136) = 0.243, p = .79; d Ftime x waiting period (2,136) = 0.304, p = 0.74; T2 directly after diagnosis, T3 after surgery, before start adjuvant therapy;
Table 4.4 Most stressful period in retrospect (T4)

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

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

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