Psychosocial adjustment in women with early stage breast cancer: the effectiveness of experiential-existential psychotherapy groups compared to social support groups

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Psychosocial interventions for women with breast cancer
Introduction

Medical knowledge about treatment of breast cancer has considerably increased the past decades [1,2]. During the late 70’s adjuvant chemo- and hormonal therapy have been introduced and screening programs have been developed [3]. Consequently, patients with breast cancer live longer, especially when diagnosed in an early disease stage. The 5, 10 and 15-year survival rates of women with breast cancer have increased markedly since the late 50’s. In the Netherlands, 32% of women younger than 70 years were still alive 10 years after the breast cancer diagnosis in the period 1955-1969. This percentage has increased up to 63%-75% in 2004 [4]. The survival advantage means that many breast cancer patients live for longer periods but at the same time have to adjust to the multiple psychological and physical sequels related to this disease [5]. Patients have to cope with the threat of a recurrence and the possibility of early death. In addition, most breast cancer patients have to undergo mutilating surgery often in combination with adjunctive therapy. As a consequence, breast cancer patients may develop psychological problems, such as anxiety and depression, and physical problems such as fatigue and early menarche [6-8]. The suffering from these psychological and physical problems stresses the importance of psychosocial treatment. Therefore, several studies have been initiated, examining the efficacy of various psychosocial intervention programs on psychological outcome in breast cancer patients [9-16]. In 1995, when the current study was initiated, studies had shown that these programs reduced emotional distress and improved coping abilities [17-19]. Psychosocial interventions appeared to be an important modality complementing medical treatment of patients with early stage breast cancer [9,11,12,15], or progressive disease [10,13,14,16].

Though the efficacy of psychosocial interventions for people with cancer had been demonstrated, it was not clear which components made them efficacious. Trijsburg and colleagues [18] concluded in their review of 22 studies that various therapeutic components were effective. Supportive and informational components, focusing on specific cancer-related problems, such as sexuality, were shown to reduce sexual problems, fatigue, psychological distress, and to preserve self-concept. Counseling, including educational and cognitive behavioral instructions and exercises, were found to have a positive effect on anxiety and depression, while behavioral interventions were thought to be especially effective in reducing anxiety and pain [18]. In social support groups or group psychotherapy, patients could also benefit from the supportive environment of the group [20]. In a meta-analytic review of 45 studies, Meyer and Mark [19] found significant effects of psychosocial interventions for psychological and functional adjustment, treatment- and disease-related symptoms and for global or compound measures.

Improvements in coping abilities, quality of social relations and emotion regulation could underline the efficacy of psychosocial interventions. This expectation was based on the findings of several studies in cancer patients and in patients with other chronic diseases,
such as AIDS. These studies showed that ineffective coping styles, lack of support and the tendency towards suppression of emotions were associated with impoverished psychological functioning [16,21-25].

A brief description of the psychosocial consequences of breast cancer and the effectiveness of interventions is presented in this chapter, separately for the following psychological outcomes: 1) psychological adjustment, 2) sexual functioning, and 3) social adjustment. At the end the rationale for the current study is given and an outline of this thesis is drawn.

Consequences of having breast cancer

Psychological consequences

A diagnosis of breast cancer is often attended with psychological problems such as anxiety and depression. According to Fallowfield [6] these psychological problems were experienced by 23% to 56% of cancer patients, which was confirmed in other studies [21,26,27]. These problems were most likely to occur shortly after diagnosis and treatment [8,28], and to decrease over time. Although most women were likely to return to their former lifestyle, up to one third experienced considerable symptoms of anxiety and depression or sexual difficulties one year after treatment [29]. Among women who have had a mastectomy, 32% reported depressive feelings one month after surgery [30]. One year later this number had declined to 20%, and two years after surgery only 13% still reported feelings of depression. These percentages were somewhat lower when it concerned symptoms of anxiety [30]. Finally, Goldberg and co-workers [7] reported a significant reduction over a one-year period in both anxiety (51% pre-operation to 27% at one year) and depression (32% pre-operation to 21% at one year).

Several factors can be predictive of psychological outcome in cancer. First of all, people are diagnosed with many different types of cancer and at various stages. This means that the psychological consequences will not be the same for every person diagnosed with cancer. The experience of physical symptoms seemed to be the most important predictive factor for the development of psychological problems [31-35]. Patients, who experienced much pain, were more likely to be depressed [31,33], reported more anxiety [33,34], more mood disturbances [32-34] and a lower quality of life [31,32] than those with less pain. A similar relationship has been reported for patients who experienced fatigue [35].

Phase of the disease, prognosis, and experiencing physical problems, such as pain and fatigue can contribute to the development of an affective disorder in cancer patients. Vinokur and colleagues [36] reported that women diagnosed with a more advanced stage of the disease, experienced more anxiety and depression and had a lower self-esteem than women diagnosed with early stage breast cancer, a result confirmed by Taylor and co-workers [37]. However, two other studies [31,38] reported that stage of the disease did not influence the
development of affective disorders. In case an effect was found for the phase of the disease, it was overshadowed by the effect of physical symptoms.

Coping style is another factor contributing to the psychological outcome of breast cancer [21,22]. A global distinction is often made into active and avoidant coping styles. Active coping refers to confrontational activities, while avoidant coping implies withdrawal actions [39]. Findings of several studies showed that women with breast cancer who normally use an active coping style were better adjusted than those who tended to avoid problems [21,22,40,41]. Which coping style is most helpful may depend on the phase of the disease [42]. Harrison and Maguire [22] concluded in their review that in the acute phase of diagnosis and treatment the use of an avoidant coping style seemed to be less anxiety-provoking than a more active, information seeking style. In the long run, however, avoidant strategies might increase the risk of psychological morbidity [43].

Finally, social support is of importance in psychological adjustment. With adequate social support, patients were found to be better adjusted psychologically, to experience a greater sense of well-being, and to show lower levels of depressive symptoms [15,16,23,24,44,45]. Most adequate support appeared to be provided by family and friends [23,24,46,47]. Conversely, inadequate social support was a risk factor for psychological morbidity [48,49].

**Sexual consequences**

During adolescence a woman creates a new body image when her breasts start to grow. This body image is disrupted by breast surgery, especially when mastectomy is carried out [50]. A consequence of breast surgery is that patients were likely to experience their bodies as disfigured, and feel as if they have lost part of their female identity [16,22,26,37,50-56]. Twenty-five percent of women with breast cancer have problems with their sexuality some time after having had breast surgery. The experience of loss of female identity is greater in women who underwent mastectomy as compared to those who had breast-conserving therapy [26,52,54,57].

Sexual problems are determined by several factors, including sexual satisfaction before surgery, stability of the relationship [56], the weight given to breast stimulation in the patient's sexual response [55,56], and on the reaction of the partner [56,58]. Other issues that can influence sexual satisfaction in breast cancer patients are mood swings [59] and the side effects of surgery and adjuvant therapy [55].

**Social consequences**

A diagnosis of breast cancer may lead to a decrease in social activities, which may in turn lead to less access to social support networks. Still, most women returned to their former lifestyle after having had surgery for breast cancer [29]. Schottenfeld and Robbins [60] reported that, irrespective of the extent of the disease, most women (87%) who underwent radical mastectomy resumed normal daily activities between one and three months after surgery.
Another 7% of the women returned to normal daily activities within 7-12 months and 6% after one year. Similar results were reported by Meyerowitz [61]. In a study comparing women with breast cancer to women with a-symptomatic disease, those with breast cancer reported greater limitations of activities. However, Vinokur and colleagues [36] found that these limitations did not appear in household activities, using private or public transport or any activities requiring the use of their arms. Since an increasing number of the women diagnosed with breast cancer had paid jobs, this appeared to be an area in which problems are likely to appear. During the recovery period, women spent less time on their jobs than before diagnosis. Most women did not consider this as a problem, since they resumed working after this period. This applied in particular to women who were diagnosed at midlife, when employment patterns had already been established or if women had jobs in which their physical limitations did not interfere with their work [62]. However, some women might experience diminished physical capacity, job loss, demotion, unwanted changes in tasks, problems with the employer and co-workers, and changes in attitudes to work [63]. Especially younger patients experienced that having cancer kept them from their jobs, and mentioned more difficulties in communicating with their colleagues [64]. In a study of functional status of long-term breast cancer survivors, 13% had difficulties getting time off from work for medical appointments, 8% had problems with their employer and 6% had problems with co-workers [65]. Even though women might experience job-related problems, returning to their job helped them to maintain a sense of normality. Therefore, returning to work could have a significant positive effect on coping with cancer [66].

Intervention strategies to alleviate psychosocial responses to breast cancer diagnosis and treatment

Various interventions techniques are used in interventions aimed to reduce the psychosocial impact of being diagnosed with breast cancer. Table 1 presents the most prominent examples of these techniques and their psychological outcome. All combinations of the techniques described in Table 1 reduce psychological distress in cancer patients, but the variety shown, makes it impossible to draw conclusions about which technique is most efficacious in reducing distress. Sexual problems related to breast cancer are not often addressed in counseling. There are several reasons for this lack. Patients may be ashamed to express worries about their sexuality when health professionals are stressing survival and control of the tumour [55]. Health professionals may also find it difficult to bring up the subject of sexuality. However, the literature on sexual counseling is quite extensive [55,58,74-77]. As only a minority of the women diagnosed with breast cancer has sexual problems, it seems inappropriate to offer special rehabilitation to all women. However, though rarely done, it still
is important to include this subject in general counseling programs if only to check whether sexual problems are an issue

Factors mediating intervention outcome
Apart from the various techniques to reduce psychological distress other factors may facilitate or hinder intervention outcome. One factor is the stage of disease. However, as we can learn from Table 1, stage of disease was not always taken into account in psychosocial interventions for cancer patients.

Time of offering psychological counseling has been rarely studied. In a study of Edgar and colleagues [12] participants were offered psychological counseling immediately after enrolling into the study or after a 4-months waiting period. Results for breast cancer patients were that at 12 months follow-up participants of both early and late start interventions experienced lower levels of distress, meaning that time of intervention was not relevant [12]. Since active coping was found to be positively associated with well-being and perceived control, promoting an active coping style was a major aim of psychosocial interventions. It used to be described as a separate and important ingredient of several psychosocial interventions for cancer patients [12,77-79] and often involved the training of standardized techniques, especially relaxation or other stress management techniques. Participating in psychosocial interventions, such as social support groups, might also indirectly lead to more active coping because patients in such groups were stimulated to active problem solving by the examples provided by other participants.

The role of social support was also an important theme in psychological interventions to reduce psychological problems [18,23,80]. Although social support seemed to be an important factor for therapeutic success, we have to be careful. In the review of Trijsburg and colleagues [18] the relationship between social support and psychological adjustment was not clarified. This means that it was not possible to conclude anything about the intermediate effect of social support on psychological adjustment. In studies of Bottemley and co-workers [15] and van der Pompe [16], no significant improvement in levels of social support was reported, concluding that group intervention provided little improvement in emotional support.

Rationale for the current study
The present study was designed on the basis of several earlier intervention studies [17-19], including a study carried out at the Helen Dowling Institute [16]. Many studies reported positive results, without being able to tell which elements of the interventions were responsible for the efficacy. The study by Van der Pompe (1997) in women with metastatic breast cancer, participating in an experiential-existential group psychotherapy (EEGP), showed that the level of distress was reduced if this level was high before intervention. The study also showed
<table>
<thead>
<tr>
<th>Authors</th>
<th>Specified intervention</th>
<th>Time of offering</th>
<th>Type of intervention and duration</th>
<th>Participants: N + cancer site</th>
<th>Stage of the disease</th>
<th>Short-term results</th>
<th>Long-term-results</th>
</tr>
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<tbody>
<tr>
<td>Bridge et al., ‘88 [67]</td>
<td>1. Relaxation 2. Relaxation and imagery</td>
<td>After receiving at least 1 session of radiotherapy</td>
<td>Individual 6 weeks</td>
<td>154: breast cancer</td>
<td>Unknown</td>
<td>Women in the relaxation and imaginary intervention were more relaxed and showed sign. lower levels of depression, especially when older</td>
<td>–</td>
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<tr>
<td>Christensen, ‘83 [68]</td>
<td>1. Communication 2. Problem-solving techniques</td>
<td>Surgery 2-3 months prior to study</td>
<td>Couple intervention 4 weeks</td>
<td>20: breast cancer</td>
<td>Non-metastatic</td>
<td>Reduced emotional discomfort, increased sexual satisfaction, reduced depression</td>
<td>–</td>
</tr>
<tr>
<td>Greer et al., ‘92 [13]</td>
<td>1. Personal meaning of cancer 2. Coping strategies</td>
<td>4-12 weeks after diagnosis or recurrence</td>
<td>Individual 6 sessions</td>
<td>156: various sites</td>
<td>Primary-metastatic</td>
<td>Positive results on coping, reduced anxiety, reduced psychological symptoms</td>
<td>4 months: reduced anxiety, reduced psychological symptoms</td>
</tr>
<tr>
<td>Authors</td>
<td>Specified intervention</td>
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</tbody>
</table>
| McArdle et al., ’96 [70]| 1. Support from nurse  
2. Support from breast cancer organisation                                      | Before surgery             | Variable                         | 272: breast cancer           | Unknown              | Improved psychosocial status when receiving support form the nurse                  |                           |
| Van der Pompe, ’97 [16]| 1. Expressing emotions  
2. Relaxation  
3. Reducing social isolation                                                        | After recurrence           | Group 13 sessions                 | 32: breast cancer            | Advanced             | Less depression when having high levels at the start and better coping when using maladaptive coping at the start |                           |
| Spiegel and Bloom, ’83 [71]| 1. Sharing mutual fears  
2. Communication  
3. Self-hypnosis  
4. Coping strategies                                                               | Variable. Average time is 24 months after diagnosis | Group Variable                  | 109: breast cancer         | Metastatic           | Reduced psychological problems and reduced pain                                     |                           |
| Tarrier and Maguire, ’84 [72]| 1. Stress management  
2. Dispatching  
3. Reintegration                                                                     | Undergoing mastectomy      | Individual 2-4 sessions           | 10: breast cancer with psychiatric problems | Unknown              | Reduced depression, reduced psychological problems and reduced anxiety            | 3 months: reduced anxiety and reduced psychological problems |
| Watson et al., ’88 [73]| 1. Emotional support  
2. Information  
3. Practical advise                                                                | After mastectomy           | Individual Variable               | 40: breast cancer            | Early stage          | Reduced depression                                                                  | 12 months: reduced depression and reduced anxiety |
that women who used maladaptive coping styles at the start of the study, changed their coping strategies [16]. However, this study neither showed which elements of the intervention yielded these outcomes. Another question, which this study could not answer, was whether the results would also apply for women with non-metastatic breast cancer. Therefore, the current study was designed. In this study two types of interventions are compared:

1. a group psychotherapy, based on experiential-existential premises
2. a social support group.

Both interventions lasted for 12 weeks and were offered to women who had been diagnosed with early stage breast cancer and had surgery for this no longer than 4 months ago. To study whether time of offering an intervention had any effect, half of the women were put on a waiting list and received either of the two interventions three months later. Women were randomly assigned to these four conditions. See figure 1 for the model of randomisation.

Comparing the interventions

There are similarities and differences between social support groups and psychotherapy groups. In both types of interventions, there is mutual support from group members and there is an exchange of disease and treatment related problems between group members. Differences are that in psychotherapy groups, the leader has a professional background, while this is not necessary in social support groups. Furthermore, in psychotherapy groups the group process is used as learning experience, there is attention for the personal meaning of experiences and emotions and problems are systematically analysed. In social support groups, this might happen as well, but is usually not the case and is more a coincidence then a regulation. Features of social support groups are the inclusion of a fair amount of psycho-education and the discussion of practical solutions for disease and treatment related problems. These features might come across in psychotherapy groups, but then it is on special request of the members or it happens as a coincidence.

Figure 1: Study design
We hypothesized that women who participated in either one of the group interventions would report a reduction in distress and sexual problems and an improvement in social functioning. However, the improvements were expected to be more prominent in women participating in group psychotherapy compared to the social support group condition. We also expected that the changes in both interventions would be significantly different from those in the waitinglist condition.

As for the delayed intervention, this was more explorative. In this part, it was studied whether the time of offering the intervention has an effect on the outcome.

**Structure of this thesis**

Chapter 2 describes the level of psychosocial adjustment at baseline. Relations between psychological adjustment, biodemographic variables, coping and social support are studied by using Structural Equation Modelling (SEM).

In chapter 3 the effect of the intervention just after completion is compared to the psychosocial status of the women who were on the waiting-list and who were about to start with their intervention.

In the 4th chapter, a comparison of intervention effects is made between participants who started with their intervention just after enrolment in the study and those who were on a waiting-list. This comparison was made after both groups of women had completed the intervention.

In chapter 5, the efficacy of both interventions, i.e. group psychotherapy and social support group, is presented. This concerns the measurements at post-intervention and at one year follow-up.

The 6th chapter describes the way women cope with their illness over time. Instead of generic coping styles, we studied coping strategies which were illness specific, as these coping strategies are more prominent during the illness phase than generic coping styles.

In the final chapter, conclusions of this study are described and an update of the literature is given. In this chapter we also give recommendations for future research.

At the end of this thesis, an appendix is included, describing the differences between the interventions.
References

4. www.IKCnet.nl/IKR.