



UvA-DARE (Digital Academic Repository)

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

Vos, P.J.

Publication date

2008

Document Version

Final published version

[Link to publication](#)

Citation for published version (APA):

Vos, P. J. (2008). *Psychosocial adjustment in women with early stage breast cancer : the effectiveness of experiential-existential psychotherapy groups compared to social support groups*.

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

Psychosocial adjustment in women with early stage breast cancer

The effectiveness of experiential-existential
psychotherapy groups compared to social support groups

Petra J. Vos



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

By P.J. Vos

Thesis (with summary in Dutch): University of Amsterdam, Faculty of Medicine

The study described in this thesis was supported by a grant of the Dutch Cancer Society (grant HDI 95-893) and was carried out at the Helen Dowling Institute, Utrecht, The Netherlands

Financial support by the Dutch Cancer Society for the publication of this thesis is gratefully acknowledged

Painting on the cover: Tamar van den Berg, moederdag 2006

Cover design: C.D. Bor

Layout and print: Optima Grafische Communicatie, Rotterdam, The Netherlands

ISBN: 978-90-9023360-4

© 2008 by Petra J. Vos, Maassluis, The Netherlands

All right reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronically or mechanically, including photocopying, recording or using any information storage and retrieval system, without the permission in writing of the author, or, when appropriate, from publishers of the publication.

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

ACADEMISCH PROEFSCHRIFT

Ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. D.C. van den Boom
ten overstaan van een door het college voor promoties
ingestelde commissie,
in het openbaar te verdedigen in de Agnietenkapel
op vrijdag 31 oktober 2008, te 12.00 uur

door

Petronella Jeanine Vos
geboren te Maassluis

Promotiecommissie

Promotor: prof. dr. J.C.J.M. de Haes

Co-promotores: dr. A.Ph. Visser
dr. B. Garssen

Overige leden: prof. dr. N.K. Aaronson
prof. dr. C.C.E. Koning
prof. dr. J. Passchier
prof. dr. A.V. Ranchor
prof. dr. E.J.Th. Rutgers
dr. F.J. Oort

Faculteit der Geneeskunde

Inhoudsopgave

Chapter 1: Psychosocial interventions for women with breast cancer	7
Chapter 2: Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling	23
Chapter 3: Psychosocial intervention for women with primary, non-metastatic breast cancer: A comparison between participants and non-participants	47
Chapter 4: Effects of delayed psychosocial interventions versus early psychosocial interventions for women with early stage breast cancer	65
Chapter 5: Effectiveness of group psychotherapy compared to social support groups in patients with primary, non-metastatic breast cancer	81
Chapter 6: Dealing with early stage breast cancer: The effects of illness specific coping strategies on psychosocial well-being over time	101
Chapter 7: Summary and general conclusion	119
Appendix: Analyzing the difference between psychotherapy groups and social support groups for breast cancer patients: the use of video recordings	133
Summary in Dutch	149
Dankwoord	157
Curriculum Vitae	163

1

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 1: Intervention studies aiming to reduce psychological distress in cancer patients

Authors	Specified intervention	Time of offering	Type of intervention and duration	Participants: N + cancer site	Stage of the disease	Short-term results	Long-term results
Bridge et al., '88 [67]	1. Relaxation 2. Relaxation and imagery	After receiving at least 1 session of radiotherapy	Individual 6 weeks	154: breast cancer	Unknown	Women in the relaxation and imaginary intervention were more relaxed and showed sign. lower levels of depression, especially when older	–
Christensen, '83 [68]	1. Communication 2. Problem-solving techniques	Surgery 2-3 months prior to study	Couple intervention 4 weeks	20: breast cancer	Non-metastatic	Reduced emotional discomfort, increased sexual satisfaction, reduced depression	–
Cocker et al., '94 [14]	1. Psycho-education 2. Cognitive restructuring 3. Relaxation 4. Assertion training 5. Coping methods	Unknown	Group intervention 12 weeks	10: breast cancer	Metastatic	Reduced depression, reduced anger	3 months: reduced depression, reduced anger
Greer et al., '92 [13]	1. Personal meaning of cancer 2. Coping strategies	4-12 weeks after diagnosis or recurrence	Individual 6 sessions	156: various sites	Primary- metastatic	Positive results on coping, reduced anxiety, reduced psychological symptoms	4 months: reduced anxiety, reduced psychological symptoms
Maguire et al., '85 [69]	1. Stress management 2. Dispatching 3. Reintegration 4. Medication	Undergoing mastectomy	Unknown	152: breast cancer with psychiatric morbidity	Unknown	Positive results on depression for those who also were prescribed medication	–

Authors	Specified intervention	Time of offering	Type of intervention and duration	Participants: N + cancer site	Stage of the disease	Short-term results	Long-term results
McArdle et al., '96 [70]	<ol style="list-style-type: none"> Support from nurse Support from breast cancer organisation 	Before surgery	Variable	272: breast cancer	Unknown	Improved psychosocial status when receiving support from the nurse	–
Van der Pompe, '97 [16]	<ol style="list-style-type: none"> Expressing emotions Relaxation 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]	<ol style="list-style-type: none"> Sharing mutual fears Communication Self-hypnosis 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]	<ol style="list-style-type: none"> Stress management Dispatching 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]	<ol style="list-style-type: none"> Emotional support Information Practical advice 	After mastectomy	Individual Variable	40: breast cancer	Early stage	Reduced depression	12 months: reduced depression and reduced anxiety

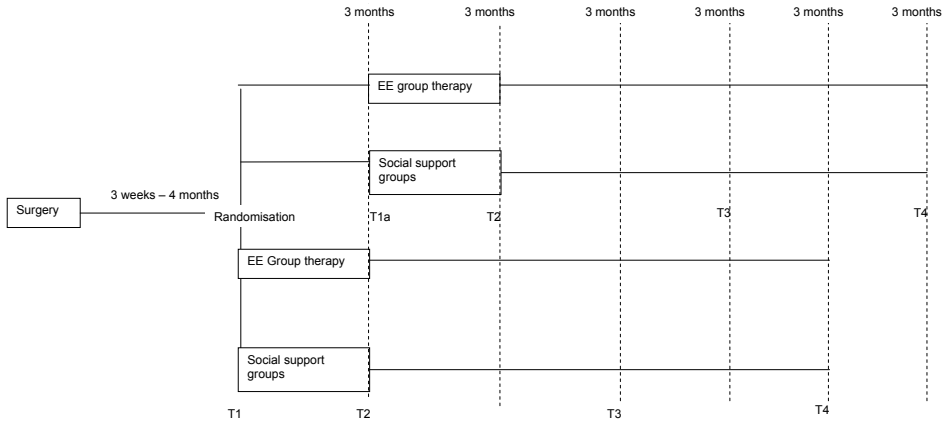


Figure 1: Study design

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 than 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.

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

1. Marchant DJ (1994). Invasive breast cancer. Surgical treatment alternatives. *Obstetrics and Gynaecology Clinics of North America*, 21: 659-679.
2. Robert NJ (1994). Adjuvant therapy in breast cancer. *Obstetrics and Gynaecology Clinics of North America*, 21: 693-707.
3. Eindhoven Cancer Registry (1995). *Cancer Incidence and Survival in the South East of the Netherlands 1955-1994*. Coebergh J.W.W., van der Heyden L.H. & Janssen-Heijnen M.L.G. (Eds) Eindhoven, The Netherlands.
4. www.IKCnet.nl/IKR.
5. Irvine D, Brown B, Crooks D, Roberts J & Browne G (1991). Psychosocial adjustment in women with breast cancer. *Cancer*, 15: 1097-1117.
6. Fallowfield L (1991). Counselling patients with cancer. In Davis H. & Fallowfield L. (Eds). *Counseling and Communication in Health Care*, John Wiley & Sons Ltd, 253-269.
7. Goldberg JA, Scott RN, Davidson PM, Murray GD, Stallard S & Maguire GP (1992). Psychological morbidity in the first year after breast surgery. *European Journal of Surgical Oncology*, 18: 327-331.
8. Couzijn AL, Ros WJG & Winnubst JAM (1990). Cancer. In Kaptein A.A., van der Ploeg H.M., Garssen B., Schreurs P.J.G. & Beunderman R. (Eds) *Behavioural Medicine*, John Wiley & Sons Ltd, 231-246.
9. Gordon WA, Freidenberg I, Diller L, Hibbard M, Wolf C, Levine L, Lipkins R, Ezrachi O & Lucido D (1980). Efficacy of psychosocial intervention with cancer patients. *Journal of Consulting and Clinical Psychology*, 48: 743-759.
10. Spiegel D, Bloom JR, & Yalom I (1981). Group support for patients with metastatic cancer. A randomised prospective outcome study. *Archives of General Psychiatry*, 38: 527-533.
11. Worden JW & Weisman AD (1984). Preventive psychological intervention with newly diagnosed cancer patients. *General Hospital Psychiatry*, 6: 243-249.
12. Edgar L, Rosberger Z & Nowlis D (1992). Coping with cancer during the first year after diagnosis. Assessment and intervention. *Cancer*, 69: 817-828.
13. Greer S, Moorey S, Baruch JDR, Watson M, Robertson BM, Mason, Rowden L, Law MG & Bliss JM (1992). Adjuvant psychological therapy for patients with cancer: A prospective randomised trial. *British Medical Journal*, 304: 675-680.
14. Cocker KL, Bell DR & Kidman AD (1994). Cognitive behaviour therapy with advanced breast cancer patients: A brief report of a pilot study. *Psycho-Oncology*, 3: 233-237.
15. Bottemley A, Hunton S, Roberts G, Jones L & Bradley C (1996). A pilot study of cognitive behavioral therapy and social support group interventions with newly diagnosed cancer patients. *Journal of Psychosocial Oncology*, 14: 65-83.
16. van der Pompe G (1997). *Mind-body Interactions in Breast Cancer. Neuroendocrine and Immune Aspects of Acute Psychological Stress and Psychosocial intervention in Breast Cancer Patients*, dissertation, Erasmus University Rotterdam, The Netherlands.
17. Andersen BL (1992). Psychological interventions for cancer patients to enhance quality of life. *Journal of Consulting and Clinical Psychology*, 66: 552-568.
18. Trijsburg RW, van Knippenberg FCE & Rijpma SE (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine*, 54: 489-517.
19. Meyer TJ & Mark MM (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, 14: 101-108.
20. van der Pompe G, Antoni MH, Visser A & Garssen B (1996). Adjustment to breast cancer: The psychobiological effects of psychosocial interventions. *Patient Education and Counseling*, 28: 209-219.
21. Greer S (1994). Psycho-oncology: It aims, achievements and future tasks. *Psycho-Oncology*, 3: 87-101.
22. Harrison J & Maguire P (1994). Predictors of psychiatric morbidity in cancer patients. *British Journal of Psychiatry*, 65: 593-598.
23. Helgeson VS & Cohen S (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15: 135-148.

24. Bloom JR & Spiegel D (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. *Social Science and Medicine*, 19: 831-837.
25. Mulder CL, Emmelkamp MG, Antoni MH, Mulder JW, Sandfort TGM & de Vries MJ (1994). Cognitive-behavioral and experiential group psychotherapy for HIV-infected homosexual men: A comparative study. *Psychosomatic Medicine*, 56: 423-431.
26. Kiebert GM, de Haes JCJM & van de Velde CJH (1991). The impact of breast conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*, 9: 1059-1070.
27. Stiefel F & Razavi D (1994). Common psychiatric disorders in cancer patients. II Anxiety and acute confusional states. *Supportive Care in Cancer*, 2: 233-237.
28. Carlsson M & Hamrin E (1994). Psychological and psychosocial aspects of breast cancer and breast cancer treatment. *Cancer Nursing*, 17: 418-428.
29. Morris T (1979). Psychological adjustment to mastectomy. *Cancer Treatment Reviews*, 6: 41-61.
30. Hughson AVM, Cooper AF, McArdle CS & Smith DC (1988). Psychosocial consequences of mastectomy: Levels of morbidity and associated factors. *Journal of Psychosomatic Research*, 32: 383-391.
31. Lansky SB, List MA, Herrmann CA, Ets Hokin EG, DasGupta TK, Wilbanks GD & Hendrickson FR (1985). Absence of major depression disorder in female cancer patients. *Journal of Clinical Oncology*, 3: 1553-1560.
32. Miaskowski C & Dibble SL (1995). The problem of pain in outpatients with breast cancer. *Oncology Nursing Forum*, 22: 791-797.
33. Ferrell BR, Grant MM, Funk BM, Otis Green SA & Garcia NJ (1998). Quality of life in breast cancer survivors: Implications for developing support services. *Oncology Nursing Forum*, 25: 887-895.
34. Spiegel D, Sands S & Koopman C (1994). Pain and depression in patients with cancer. *Cancer*, 74: 2570-2578.
35. Irvine DM, Vincent L, Graydon JE & Bubela N (1998). Fatigue in women with breast cancer receiving radiation therapy. *Cancer Nursing*, 21: 127-135.
36. Vinokur AD, Threatt BA, Caplan RD & Zimmerman BL (1989). Physical and psychosocial functioning and adjustment to breast cancer. Long-term follow-up of a screening population. *Cancer*, 63: 394-405.
37. Taylor SE, Lichtman RR, Wood JV, Bluming AZ, Dosik GM & Leibowitz RL (1985). Illness-related and treatment related factors in the psychological adjustment to breast cancer. *Cancer*, 55: 2506-2513.
38. Hopwood P, Howell A & Maguire P (1991). Psychiatric Morbidity in patients with advanced cancer of the breast: Prevalence measured by two self-rating questionnaires. *British Journal of Cancer*, 64: 349-352.
39. de Groot K. (1996). *Predicting Recovery from Surgery. The influence of Preoperative Stress and Mental Preparation on Postoperative State*, dissertation, Erasmus Universiteit Rotterdam, The Netherlands
40. Weisman AD (1976). Early diagnosis of vulnerability in cancer patients. *The American Journal of the Medical Sciences*, 271: 187-196.
41. Friedman LC, Baer PE, Lewy A, Lane M & Smith FE (1988). Predictors of psychosocial adjustment to breast cancer. *Journal of Psychosocial Oncology*, 6: 75-94.
42. Greer S (1992). The management of denial in cancer patients. *Oncology*, 6: 33-40.
43. Heim E, Augustiny KF, Blaser A, Bürki C, Kühne D, Rothenbühler M, Schaffner L & Valach L (1987). Coping with breast cancer - a longitudinal prospective study. *Psychotherapy and Psychosomatics*, 48: 44-59.
44. Hoskins CN, Baker S, Sherman D, Bohlander J, Bookbinder M, Budin W, Ekstrom D, Knauer C & Maislin G (1996). Social support and patterns of adjustment to breast cancer. *Scholarly Inquiry for Nursing Practice: An International Journal*, 10: 99-123.
45. Lichtman RR, Taylor SE & Wood JV (1987). Social support and marital adjustment to breast cancer. *Journal of Psychosocial Oncology*, 5: 47-74.
46. Spiegel D & Kato PM (1996). Psychological influences on cancer incidence and progression. *Harvard Reviews in Psychiatry*, 4: 10-26.

47. Smyth MM, McCaughan E & Harrison S (1995). Women's perception of their experiences with breast cancer: Are their needs being addressed? *European Journal of Cancer Care*, 4: 86-92.
48. Worden JW (1991). *Grief Counselling and Grief Therapy. A Handbook for the Mental Health Practitioner*. Second Edition. Springer Publishing Company, Inc, New York.
49. Stanton AL & Snider PR (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology*, 12: 16-23.
50. Gyllensköld K & Glaumann B (1985). A pilot study of some psychological aspects of subcutaneous mastectomy. *Scandinavian Journal of Plastic and Reconstructive Surgery*, 19: 283-288.
51. Hahn DM, Oxman TE, Ahles TA, Furstenberg CT & Stuke TA (1985). Social support adequacy and depression in older patients with metastatic cancer. *Psycho-Oncology*, 4: 213-221.
52. Kemeny MM, Wellisch DK & Schain WS (1988). Psychosocial outcome in a randomized surgical trial for treatment of primary breast cancer. *Cancer*, 62: 1231-1237.
53. Margolis G, Goodman RL & Rubin A (1990). Psychological effects of breast-conserving cancer treatment and mastectomy. *Psychosomatics*, 31: 33-39.
54. Meyer L & Aspergen K (1989). Long-term psychological sequelae of mastectomy and breast conserving treatment for breast cancer. *Acta Oncologica*, 28: 13-18.
55. Mantell JE (1982). Sexuality and cancer. In Cohen J. (Ed). *Psychosocial Aspects of Cancer*. Raven Press, New York, 235-247.
56. Walbroehl GS (1985). Sexuality in cancer patients. *APF*, 31: 153-158.
57. Schover LR (1991). The impact of breast cancer on sexuality, body image, and intimate relationships. *CA - A Cancer Journal for Clinicians*, 41: 112-120.
58. Singer Kaplan H (1992). A neglected issue: The sexual side effects of current treatment for breast cancer. *Journal of Sex and Marital Therapy*, 18: 3-19.
59. von Eschenbach AC & Schover LR (1984). The role of sexual rehabilitation in the treatment of patients with cancer. *Cancer*, 54: 2662-2667.
60. Schottenfeld D & Robbins GF (1970). Quality of survival among patients who have had radical mastectomy. *Cancer*, 26: 650-654.
61. Meyerowitz BE (1980). Psychosocial correlates of breast cancer and its treatment. *Psychological Bulletin*, 87: 108-131.
62. Andersen BL, Anderson B & deProse C (1989). Controlled prospective longitudinal study of women with breast cancer: II Psychological outcomes. *Journal of Consulting and Clinical Psychology*, 57: 692-697.
63. Maunsell E, Brisson C, Dubois L, Lauzier S & Frazer A (1999). Work problems after breast cancer: An exploratory qualitative study. *Psycho-Oncology*, 8: 467-473.
64. Ganz PA, Coscarelli Shag C & Heinrich (1985). The psychosocial impact of cancer on the elderly: A comparison with younger patients. *Journal of the American Geriatrics Society*, 33: 429-435.
65. Polinsky ML (1994). Functional status of long-term breast cancer survivors: Demonstrating chronicity. *Health & Social Work*, 19: 165-173.
66. Ferrel BR, Grant M, Funk B, Otis-Green S & Garcia N (1997). Quality of life in breast cancer. Part I: Physical and social well-being. *Cancer Nursing*, 20: 398-408.
67. Bridge LR, Benson P, Pietroni PC & Priest RG (1988). Relaxation training and imagery in the treatment of breast cancer. *British Medical Journal*, 297: 1169-1172.
68. Christensen DN (1983). Postmastectomy couple counselling: An outcome study of a structured treatment protocol. *Journal of Sex & Marital Therapy*, 9: 266-275.
69. Maguire P, Hopwood P, Tarrier N & Howell T (1985). Treatment of depression in cancer patients. *Acta Psychiatrica Scandinavica*, 72: 81-84.
70. McArdle JMC, George WD, McArdle CS, Smith DC, Moodie AR, Hughson AVM & Murray GD (1996). Psychological support for patients undergoing breast cancer surgery: A randomised study. *British Medical Journal*, 312: 813-816.
71. Spiegel D & Bloom JR (1983). Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosomatic Medicine*, 45: 333-339.
72. Tarrier N & Maguire P (1984). Treatment of psychological distress following mastectomy: An initial report. *Behavioural Research in Therapy*, 22: 81-84.
73. Watson M, Denton S, Baum M & Greer S (1988). Counselling breast cancer patients: A specialist nurse service. *Counselling Psychology Quarterly*, 1: 25-34.

74. Weijmar Schultz WCM & van de Wiel HBM (1991). *Sexual Function after Gynaecological Cancer Treatment*, dissertation, Rijksuniversiteit Groningen, The Netherlands.
75. Alfonso CE, Cohen MA, Levin M, Simon K, Abraham N, & Metropolitan Center Psychooncology Study Group (1997). Sexual dysfunction in cancer patients: A collaborative psychooncology project. *International Journal of Mental Health*, 26: 90-98.
76. Auchincloss S (1991). Sexual dysfunction after cancer treatment. *Journal of Psychosocial Oncology*, 16: 23-41.
77. Cain EN, Kohorn EI, Quinlan DM, Litmer K & Schwartz PE (1986). Psychological benefits of a cancer support group. *Cancer*, 57: 183-189.
78. Cunningham AJ & Tocco EK (1989). A randomized trial of group psychoeducational therapy for cancer. *Patient Education and Counselling*, 14: 101-114.
79. Fawzy FI, Cousins N, Fawzy NW, Kemeny ME, Elashoff R & Morton D (1990). A structured psychiatric intervention for cancer patients. *Archives of General Psychiatry*, 47: 720-725.
80. Hitch PJ, Fielding RG & Llewelyn SP (1994). Effectiveness of self-help and support groups for cancer patients: A review. *Psychology and Health*, 9: 437-448.

2

Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling

Petra J. Vos

Bert Garssen

Adriaan P. Visser

Hugo J. Duivenvoorden

Hanneke C.J.M. de Haes

Abstract

In many women, the diagnosis of breast cancer leads to psychosocial adjustment problems. Biodemographic variables, coping and social support are factors which influence psychosocial adjustment. The main objective of the present study was to identify and estimate the associations between psychosocial adjustment and biodemographic variables, coping and social support by using Structural Equation Modelling (SEM). Eighty-seven women with newly diagnosed early stage breast cancer completed several questionnaires covering these areas. It appeared that in the period shortly after surgery, coping style, especially illness specific coping, is of high relevance for psychosocial adjustment. In our study, we could not confirm the positive role of social support found in other studies on psychosocial adjustment. Biodemographic variables had both direct and indirect associations with psychosocial adjustment: Older women and women who had had breast-conserving treatment used a more optimistic coping style; the latter group also reported higher body image. Finally, women with a more advanced stage of disease reported a reduction in recreational activities.

Introduction

Patients diagnosed with cancer may experience problems in several areas, notably emotional functioning (i.e. anxiety, depression, grief, helplessness, anger, confusion and low self-esteem), psychosexual functioning (i.e. impairments in sexual functioning, less joy in sexual experiences and problems in the relation with partner), and social functioning. Studies indicate that just after diagnosis and medical treatment, emotional problems are experienced by 23% to 56% of the breast cancer patients [1-5]. In the long run, emotional problems decrease in most women to a level found on average in patients with other chronic diseases and in the normal population, but up to one third experience longer lasting symptoms of depression and anxiety [6-9].

After surgery, women may experience their body as disfigured and may feel as if they have lost part of their female identity [1,10,11]. Most studies indicate that the type of surgery has no influence on the level of emotional problems in breast cancer patients [1,10,12]. However, it may have an effect in specific areas. Between 25% and 78% of the women who had had mastectomy report problems with body image and female identity, even some years after treatment. For women who underwent breast-conserving treatment, this number was only 3% to 16% [10,12-15]. Mastectomy also led to greater problems with sexuality [15]. Sexual problems, however, may also directly emanate from the side effects of adjuvant therapies, especially chemotherapy [15-17] and hormonal therapy [17-19].

Social functioning is an area in which the least problems arise. A minority of women with breast cancer report problems with household activities [20], their jobs [21, 22], and leisure activities [23]. These problems are prominent in the period just after diagnosis and during treatment, but decrease over time [20, 24,25].

Variation in level to adjustment problems might be partly explained by disease related and socio-demographic factors, especially: Disease stage, number of affected lymph nodes, type of surgery, age, socio-economic status, education and marital status. However, reported studies do not allow for a clear conclusion. Although some authors found that women diagnosed with a more advanced stage of breast cancer experienced more anxiety and depression than women with better prognoses [13,25], others failed to find such a relationship [26, 27]. Findings are also inconclusive for socio-demographic factors. The level of education and income are not associated with psychosocial problems, while age and marital status have in some studies been found to be related both positively and negatively to psychosocial adjustment. In other studies such a relationship could not be demonstrated [5,6,28,29].

Major factors for psychosocial adjustment seem to be the patients' coping style and the level of experienced support. Several studies have found that an active coping style (i.e. information seeking, a confronting approach to the illness, and seeking social support) is related to relatively adequate psychosocial adjustment [3,30-33], although other studies failed to find such relationships [34,35]. Carver and co-workers (1993) for instance, found that active

coping was a frequently used coping style in women recently diagnosed with breast cancer, but they could not demonstrate a relationship with the distress level [34]. Avoidant or passive coping strategies appeared to be consistently related to higher levels of emotional distress [30,32,33,35-37].

The relationship between active coping and psychosocial adjustment might depend on the phase in the illness process and appear to be not always the same as reported in the general coping literature. Harrison and Maguire (1994) suggested, for instance, that, although active coping strategies are generally linked to better adjustment, this appeared not to be the case in the acute phase of the disease. In this phase, active coping strategies may be too confronting and may even result in lower levels of adjustment than using avoidant coping strategies [38]. Meyerowitz (1980) concluded in a study among women with breast cancer that coping mechanisms which appear to be adaptive after mastectomy, were not always those generally considered to be adequate coping strategies in dealing with other stresses [20]. An example is denial of emotions. Denial is considered to be a relatively adequate coping strategy just after diagnosis, but is reported to be an ineffective coping style with respect to stressful events in general [39,40]. Apparently, the stressful nature of breast cancer and its treatment requires women to use other coping mechanisms than those used in dealing with other stressful events.

The role of social support in psychosocial adjustment is demonstrated in many studies. Patients experiencing adequate social support, especially from family and close friends are better adjusted, experience a greater sense of well-being, and report lower levels of depressive symptoms [41-45].

Schnoll and co-workers (1998) advocated the necessity of testing several factors simultaneously in a model [36]. The advantage of model identification and testing is the possibility of explaining both the direct and indirect effects of demographic and medical factors on adjustment. As the number of variables had to be limited, given their sample size, Schnoll and colleagues (1998) only tested the direct and indirect effect of age, stage of disease, and coping style on psychological distress. A second limitation of their study was that they only used anxiety, depression and impaired quality of life as dependent variables in their model. They chose to omit social support from their model testing, with the argument that findings in the literature concerning its effect on psychosocial adjustment are clear and needed no further examination [36]. However, the abovementioned literature review suggests that psychosexual and social adjustment should be added as dependent variables.

The main objective of the present study is to identify and estimate the interrelationship of demographic variables, coping style and social support on psychological, psychosexual and social adjustment to early stage breast cancer.

Methods

Subjects and procedures

Patients were recruited from several hospitals in the region of Rotterdam, The Netherlands for a long-term intervention study. Potential participants were women between 18 and 70 years of age, who had had surgery for primary breast cancer no longer than four months ago, no distant metastases, sufficient knowledge of the Dutch language, and no psychiatric illness, such as schizophrenia, hypochondria as defined by DSM-IV. An oncology nurse, who also judged their mental status, informed them about the study. The women were given an information package. If a woman was not interested in participating, she could mention this by returning an answering-form. If this form was not returned within three weeks, the investigator attempted to contact the women. During this telephone contact, the study objective and procedures were explained and patients were asked to participate. If consenting, an appointment was made for the first interview. During this interview women were asked to sign a written informed consent. At the end of the interview, a questionnaire was handed over. Women were asked to complete this questionnaire at their earliest convenience and return it by mail in a pre-stamped envelope. In case the questionnaires were not returned within four weeks, a reminder was sent.

Measures

In this study, independent variables were medical and demographic variables. These data were obtained from a general questionnaire containing anamnestic questions (size of tumour, date of diagnosis and surgery, type of surgery, number of affected lymph nodes, adjuvant therapy) and demographic questions (age, education, marital status, work status). The oncology nurse, who referred patients to the researcher, checked the information in medical records.

Coping and social support were considered to be mediating variables. These variables were thought to be influenced by the medical and demographic variables, but also to have an effect on the outcome variables.

Coping was measured with two questionnaires. Generic coping was measured with the shortened 19-item version of the Utrecht Coping List (UCL) [46]. It covers three dimensions of coping: 1) Active coping, in which patients actively confront a problem and try to solve it (5 items; $\alpha = 0.83$); 2) Emotion Focused coping, in which patients try to reduce their stress by expressing their emotions and seeking social support (5 items; $\alpha = 0.75$); and 3) Palliative coping, a strategy in which patients seek distraction in order not to think about their problems (4 items; $\alpha = 0.70$). It should be scored on a 4-point scale. Higher scores represent a more frequent use of that particular coping strategy. Reliability and validity are adequate for the Dutch population (Schreurs, 1996; personal communication)

Illness specific coping was assessed with the Health and Diseases Inventories (HDI), designed especially for cancer patients [47]. The coping with illness questionnaire consists of three subscales: 1) Optimistic Attitudes (17 items; $\alpha = 0.74$): Persons who score high on this subscale have a self-confident and optimistic attitude toward life, they enjoy life and have confidence in the future, they also act as if nothing has happened; 2) Illness Orientated coping (6 items; $\alpha = 0.65$), indicating a preoccupation with what is happening in one's body and having a negative, fatalistic idea about the disease; 3) Repressive coping (7 items; $\alpha = 0.85$), which measures non-expression of negative emotions, and asking for support and attention of others. The HDI should be scored on 6-point scale. Higher scores represent a more frequent use of the pertinent coping strategy. Both reliability and validity of this questionnaire are adequate [47].

Social support was measured with the Social Network Questionnaire (SNQ) [48]. This questionnaire measures the perceived support in specific areas, as derived from a factor analytic study. The SNQ addresses support by: 1) Significant others, such as partner, family and close friends (3 items; $\alpha = 0.43$); 2) Persons from the medical setting, such as doctors and other medical personnel (4 items; $\alpha = 0.65$); and 3) Others, such as psychosocial workers, colleagues and strangers (4 items; $\alpha = 0.14$). The questionnaire is scored on a 5-point scale, with '0' meaning not applicable. Reliability of the questionnaire is sufficient.

The dependent variables in this study were the psychosocial adjustment variables, which were covered by three scales:

Emotional adjustment was measured with the Dutch version of the Profile of Mood States (POMS) [49], which measures mood states in five areas: Depression (8 items; $\alpha = 0.89$), Anger (7 items; $\alpha = 0.91$), Fatigue (6 items; $\alpha = 0.91$), Tension (6 items; $\alpha = 0.89$), and Vigour (5 items; $\alpha = 0.80$). A higher score indicates that a particular mood is more often experienced. The POMS should be scored on a 5-point scale. Reliability and validity of this shortened Dutch version are adequate for a Dutch population [49].

Psychosexual functioning was measured with the subscales Sexual Functioning (2 items; $\alpha = 0.81$) and Body Image (4 items; $\alpha = 0.89$) of the breast cancer specific module (Quality of Life Questionnaire (QLQ)-BR32) of the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-30, a 30-item questionnaire, designed especially to evaluate quality of life in cancer patients [50,51]. It includes questions about side effects of different treatment modalities, body image and sexuality and should be scored on a 4-point scale. Higher scores on the subscale Body Image represent worse level of functioning, while higher scores in the subscale Sexual Functioning represent a better level of functioning. Reliability and validity of the questionnaire is satisfactory for a Dutch population of women with breast cancer [50].

Social adjustment was measured with the subscales Social Interactions (20 items; $\alpha = 0.75$) and Recreation (8 items; $\alpha = 0.75$) of the Sickness Impact Profile (SIP) [52]. This is a daily functioning questionnaire, which describes the impact of illness on behavior in 12 aspects. In this questionnaire, statements should be answered with 'right' or 'not right'. Higher scores represent more impact of the illness. Reliability and validity for the SIP are good [52].

All data were collected at the same time point, that is within four months after surgery, and there are, therefore, no time effects.

Statistical analyses

Missing data on item level were replaced, but only if no more than 25% of item scores for a particular subscale and a particular participant were missing. A missing value for a particular item was replaced by the mean score of the remaining item scores for that subscale of that person, multiplied by the mean of the scores of the other participants on that particular item. This score was then divided by the overall mean of that subscale [Garszen, 1999; personal communication].

Because of the ratio of variables in the model and the number of participants, we have tried to limit the number of variables in the analyses. Intercorrelation coefficients were determined for the six subscales of the coping measures (UCL and HDI) and the subscales of the POMS. In case of high interrelationships, principal component analyses were performed to combine subscales into higher order dimensions.

The Structural Equation Modelling (SEM) approach was applied to explore the interrelationships of the variables [53]. This approach involves the examination of several models in order to identify the most plausible model and to estimate their individual parameters. The structural model concerns the direct and indirect relationships between independent variables and dependent variables [54]. As the number of patients was limited, only interrelationships of observed (manifest) variables were explored.

The analyses for constructing structural equation models were conducted with the Mplus program [55]

Strategy of analyses

The process of fitting SEM started with the construction of a theoretically based model. It was hypothesized that the psychosocial outcome variables (i.e. Distress, Vitality, Body Image, Sexual Functioning, Recreation and Social Interactions) were associated with coping and social support. We also hypothesized that 'Age', 'Stage of disease' and 'Type of surgery' were associated with coping and social support, and were, directly or indirectly through their association with coping and social support, associated with the psychosocial outcome variables (see Figure 1). The main objective was therefore, to identify, specify and estimate the structural relationship between coping and social support and psychosocial adjustment. A second objective was to estimate the importance of the biodemographic and medical data.

In the first step, we simultaneously explored all possible relationships between coping and social support on the one hand and psychosocial adjustment on the other hand. Coping comprised the dimensions generic coping and disease specific coping. Psychosocial adjustment was unravelled into the dimensions psychological functioning, psychosexual functioning, and social functioning respectively.

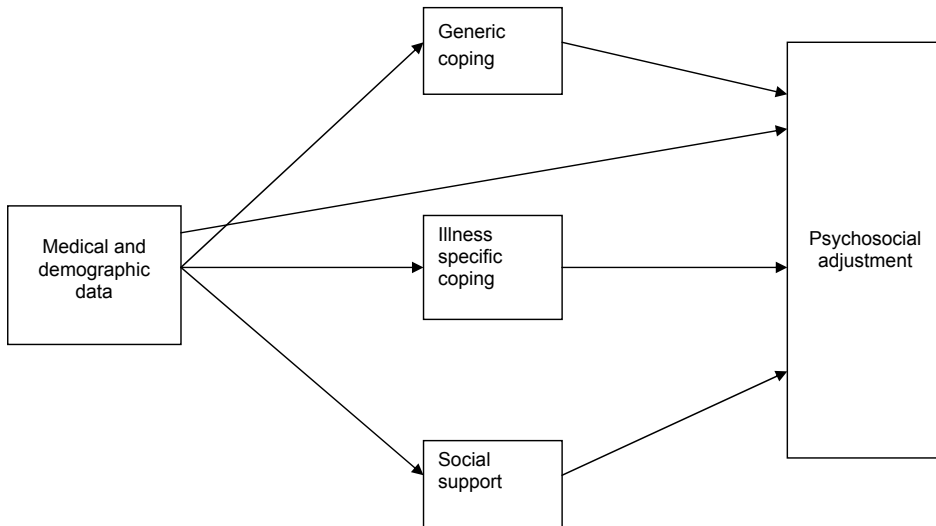


Figure 1: Hypothesized model

The second step was that for each individual dimension of coping (i.e. generic and illness specific coping) and social support it was explored whether it was acceptable to fix the regression coefficient at zero, first step-by-step, then two regression coefficients simultaneously, and finally all three together. This strategy was performed for each coping dimension and the social support dimension separately, while the regression coefficients of the other dimensions were preserved, and were retained in the model as covariate sets. A model will be rejected in case it does not meet the minimum criteria of goodness of fit. We went on testing with fixing dimensions of coping and social support at zero, until we found no more meaningful improvement in relation with earlier tested models.

For each model estimated, the fit was evaluated by examination of the individual parameter estimates, measures of overall fit and detailed assessment of fit (fitted and standardized residuals and modification indices). Different measures of goodness of fit are mentioned in the literature [53]. In this study, the following performance measures were selected to test the hypothesized models: 1) chi-square for model fit and p-value; 2) chi-square for model fit divided by degrees of freedom (a value of < 1.5 is acceptable); 3) Comparative Fit Index (CFI; a value of > 0.90 suggests a close fit, maximum value is 1.00) [56]; 4) Tucker-Lewis Index (TLI; a value of > 0.90 suggests a close fit, maximum value has to be 1.00) [57]; 5) root mean squares error of approximation (RMSEA; a value of 0.05 indicates a close fit) [58]; and 6) standardized root mean squares of residuals (SRMR; a value of < 0.05 indicates a good fit). The final model should be a model that fits the data of the sample reasonably well and in which all parameters are meaningful and substantively interpretable.

Results

Sample description

Two hundred and fifty one eligible women were contacted by the investigators by telephone. The reasons for not participating of 164 women were: 1) not interested (15.9%), 2) having enough support (15.9%), 3) being too emotionally distressed (8.5%), 4) could not be reached by telephone (11.6%), 5) other reasons such as distance and time (16.5%), and 6) unknown (32.5%). Eighty-seven women (34.7%) enrolled into the study. These were all women with a primary breast cancer diagnosis. None of these women had distant metastases. Twenty-eight women had affected lymph nodes. Almost two-third of the women in our study had had a mastectomy (64.4%). Only four had had a reconstruction at the time of interview. Of the 87 women, 36 (41.4%) did not receive adjuvant treatment. Twenty-one women (24.1%) received radiotherapy, ten women (11.5%) underwent chemotherapy and two women (2.3%) received hormonal therapy as the only adjuvant treatment after surgery. Eighteen women (20.7%) received a combination of the abovementioned treatments. The mean age was 50.0 years (range 29-68; SD 7,92). Most women had finished secondary school as their highest education (71.2%). Of the 64 women who had a partner, 8 were not living with their partner. Of the 21 women who were single, 4 were never married, 15 women were divorced and 2 women were widowed. Medical and demographic data are summarized in Table 1.

Data reduction

Pearson correlation-coefficients revealed the relation between the six coping subscales and the subscales of the POMS. The coping subscales appeared to be relatively independent. Therefore, data-reduction would yield too much loss of information. Intercorrelations of the POMS-subscales were all statistically significant, with the lowest correlation being 0.35 between the subscales Vigour and Tension. Therefore, a Principal Component Analysis with Varimax Rotation was performed on the subscales of the POMS, which resulted in two independent components (Table 2). The first component represents Distress and is formed by the subscales Depression, Anger and Tension. The second component is formed by the subscales (reverse of) Fatigue and Vigour and represents Vitality. Higher scores represent more distress and worse vitality. For both components, the means were calculated and used in the following analyses.

Correlations

Table 3 shows the observed correlations for all the psychosocial variables in our analyses. From Table 3 it can be concluded that the psychosocial adjustment scales are mostly significantly correlated with each other. It is also striking that the mediating factors coping and social support, with exception of illness specific coping, are not correlated with the psychosocial

Table 1: Medical and demographic characteristics

	No.	%
Total patients	87	100
Time since surgery (weeks)		
Mean (range)	11.8 (3-49)	
Stage		
0	3	3.4
I	27	31.0
II	45	51.7
III	4	4.5
Missing	8	9.2
Number of affected lymph nodes		
0	58	66.7
1-4	20	22.9
>4	8	9.0
Missing	1	1.1
Type of surgery		
Breast conserving therapy	31	35.6
Mastectomy	56	64.4
Adjuvant treatment		
Radiotherapy	21	24.1
Chemotherapy	10	11.5
Hormonal therapy	2	2.3
Chemotherapy and radiotherapy	10	11.5
Chemotherapy and hormonal therapy	2	2.3
Radiotherapy and hormonal therapy	3	3.4
Chemotherapy, radiotherapy and hormonal therapy	3	3.4
Age (years)		
Mean (range)	50.0 (29-68)	
Highest education		
Primary school	6	6.9
Secondary school	62	71.2
Higher education	16	18.4
Missing	3	3.4
Marital status		
Partner	64	73.6
Single	21	24.1
Missing	2	2.3

Table 2: Factor loadings of the POMS

POMS subscales	Factor I Distress	Factor II Vitality
Depression	0.87	0.30
Anger	0.78	0.28
Fatigue	0.41	0.78
Tension	0.86	0.19
Vigour	-0.17	-0.92

adjustment scales. Sexual Functioning appears to be correlated with none of the biomedical, coping and social support variables.

From the biomedical variables, Age was significantly correlated with Social Interactions ($r = -0.22$) and with Optimistic Attitude ($r = 0.27$). Stage of the disease was significantly correlated with Social Interactions ($r = 0.25$) and with Age ($r = -0.26$). Finally, Type of surgery was significantly correlated with Distress ($r = 0.22$) and with Body Image ($r = 0.37$).

Results of Modelling

The first step was testing the hypothesized model. Based on results of this analysis, and on the correlations presented in Table 3, it appeared to be necessary to explore other models. As can be concluded from Table 4, the first model we tested had no unique solution, due to the fact that no degrees of freedom were left.

In the next step, a series of analyses were performed, in which the regression coefficient of one dimension of coping and social support and one or more dimensions of psychosocial adjustment were fixed at zero. As can be read from Table 4, when fixing the regression coefficient of illness specific coping and any of the psychological adjustment concepts (i.e. psychological, psychosexual or social adjustment) at zero, the solutions had to be rejected on almost all goodness of fit tests performed. For generic coping, the results were slightly better. But also for these solutions, most goodness of fit tests did not meet the minimum criteria for acceptance of model fit; as a consequence, these models had to be rejected too. The series of models in which the paths between social support and psychosocial adjustment were fixed, did result in satisfactory solutions, especially when the paths between social support and psychosexual adjustment were fixed at zero.

Because the solutions of the first series of model testing were not satisfactory, a second series of model testing were performed, in which two dimensions of psychosocial adjustment were fixed at zero. Results for illness specific coping were that all the models in which the regression coefficients were fixed at zero, had to be rejected based on results of goodness of fit tests (Table 4). On the basis of these results, and on the results of the zero order correlations (Table 3), which showed that illness specific coping was significantly correlated with almost all psychosocial adjustment variables, it was decided not to carry out more analyses in which regression coefficients of illness specific coping and any dimension of psychosocial adjustment were fixed at zero.

The results for generic coping were somewhat better than they were in the first series, but most goodness of fit tests again did not meet the criteria. In these series, the results for social support were satisfactory too. For social support, in the second series all tests resulted models that met the goodness of fit criteria. However, based on the goodness of fit tests of the first series, results in the previous step were slightly better.

In the next series of model testing, all the dimensions of psychosocial adjustment were fixed at zero. The results for generic coping were again not satisfactory. Based on the goodness

Table 3: Correlation matrix of psychological and background variables (n = 87)^a

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Distress	4.4 ±4.4														
2. Vitality	-0.58**	13.9±4.6													
3. Body Image	-0.52**	0.34**	73.8±26.2												
4. Sexual funct	0.28**	-0.35**	NS	74.3±21.9											
5. Recreation	0.37**	-0.59**	-0.22*	0.39**	3.8±2.1										
6. Social Int	0.56**	-0.47**	-0.30**	0.25*	0.57**	3.9±3.2									
7. Active coping	NS	NS	NS	NS	NS	NS	14.0±2.7								
8. Emotional coping	0.26*	NS	NS	NS	NS	NS	0.42**	11.4±2.6							
9. Palliative coping	0.22*	NS	NS	NS	NS	NS	0.27*	0.28*	8.8±2.3						
10. Optimistic Attitude	-0.38**	0.30**	0.50**	NS	-0.27*	-0.48**	0.30**	NS	NS	70.9±8.9					
11. Illness Orientated. Coping	0.53**	-0.34**	-0.37**	NS	0.22*	0.23*	NS	0.22*	NS	-0.28*	20.5±5.4				
12. Repressive coping	0.31**	-0.38**	-0.24*	NS	NS	0.26*	-0.25*	-0.41**	NS	-0.31**	0.27*	21.1±8.2			
13. Significant Others	NS	NS	NS	NS	NS	NS	NS	0.23*	NS	NS	NS	-0.28**	10.0±1.7		
14. Medical Services	NS	NS	NS	NS	NS	NS	0.22*	NS	NS	0.25*	NS	NS	NS	9.3±3.0	
15. Others	NS	NS	NS	NS	NS	0.26*	NS	NS	NS	NS	NS	NS	NS	0.24*	6.6±2.1

** p<0.01 (two-tailed); * p<0.05 (two-tailed);^a Means and standard deviations of the interval variables and frequencies for the categorical variables are shown in bold on the main diagonal

Table 4: Results of models search: goodness of fit tests

Model	X2	df	X2/df	p-value	CFI	TLI	RMSEA (95% CI)	SRMR
No paths fixed	0.000	0	-	0.000	1.000	1.000	0.000 (0.00 to 0.00)	0.000
One series of paths fixed; between:								
1. Illness specific coping ¹ and psychological adj.	49.826	6	8.30	0.000	0.874	-2.149	0.290 (0.22 to 0.37)	0.084
2. Illness specific coping ¹ and psychosexual adj.	23.427	6	3.90	0.001	0.950	-0.252	0.183 (0.11 to 0.26)	0.048
3. Illness specific coping ¹ and social adj.	28.859	6	4.81	0.000	0.934	-0.642	0.209 (0.14 to 0.29)	0.061
4. Generic coping ² and psychological adj.	20.825	6	3.47	0.002	0.957	-0.065	0.169 (0.09 to 0.25)	0.041
5. Generic coping ² and psychosexual adj.	2.608	6	0.43	0.856	1.000	1.244	0.000 (0.00 to 0.08)	0.013
6. Generic coping ² and social adj.	13.418	6	2.24	0.037	0.979	0.467	0.119 (0.03 to 0.21)	0.030
7. Social support and psychological adj.	6.763	6	1.13	0.343	0.998	0.945	0.038 (0.00 to 0.15)	0.014
8. Social support and psychosexual adj.	6.433	6	1.07	0.376	0.999	0.969	0.029 (0.00 to 0.15)	0.016
9. Social support and social adj.	8.447	6	1.41	0.207	0.993	0.824	0.068 (0.00 to 0.17)	0.019
Two series of paths fixed, between:								
10. Illness specific coping ¹ and psychological/psychosexual adj.	61.206	12	5.11	0.000	0.859	-0.768	0.217 (0.17 to 0.27)	0.080
11. Illness specific coping ¹ and psychological/social adj.	64.516	12	5.38	0.000	0.849	-0.887	0.224 (0.17 to 0.28)	0.090
12. Illness specific coping ¹ and psychosexual/social adj.	46.453	12	3.87	0.000	0.901	-0.238	0.182 (0.13 to 0.24)	0.068
13. Generic coping ² and psychological/psychosexual adj.	29.640	12	2.47	0.003	0.949	0.366	0.130 (0.07 to 0.19)	0.037
14. Generic coping ² and psychological/social adj.	26.775	12	2.23	0.008	0.958	0.469	0.119 (0.06 to 0.18)	0.045
15. Generic coping ² and psychosexual/social adj.	20.198	12	1.73	0.063	0.976	0.705	0.089 (0.00 to 0.15)	0.028
16. Social support and psychological/psychosexual adj.	13.726	12	1.14	0.319	0.995	0.938	0.041 (0.00 to 0.12)	0.021
17. Social support and psychological/social adj.	16.046	12	1.34	0.189	0.988	0.855	0.062 (0.00 to 0.13)	0.022
18. Social support and psychosexual/social adj.	14.506	12	1.21	0.270	0.993	0.910	0.049 (0.00 to 0.13)	0.023
Three paths fixed, between:								
19. Generic coping ² and psychosocial adj.	37.886	18	2.10	0.004	0.943	0.524	0.113 (0.06 to 0.16)	0.041
20. Social support and psychosocial adj.	22.312	18	1.24	0.218	0.988	0.897	0.052 (0.00 to 0.11)	0.026

CFI = Comparative Fit Index; TLI = Tucker Lewis Index; RMSEA = Root Mean Square Error of Approximation; SRMR = Standardized Root Mean Square Residual

¹ Illness specific coping encompasses the following coping strategies: Optimistic Attitude, Repressive Coping and Illness Orientated Coping

² Generic coping encompasses the following coping strategies: Active coping, Emotion-Focused Coping and Palliative Coping.

of fit tests, the models in which the path between generic coping and all the psychosocial adjustment concepts were fixed at zero, had to be rejected. In the models in which the paths between social support and all psychosocial adjustment concepts were fixed at zero, goodness of fit tests were satisfactory, but compared to the models of the previous steps, this model did not show any improvement.

No further analyses were carried out, since it appeared that fixing more paths to zero, would not improve the goodness of fit of the models to be tested. Following the results of these analyses, we decided that the model in which the paths between social support and psychosocial adjustment were fixed at zero was the most satisfactory in our study group (see Table 4). This model is presented in Figure 2.

Biomedical variables

As can be read from Figure 2, biomedical variables were both directly and indirectly associated with some of the indicators of psychosocial adjustment. Stage of the disease was associ-

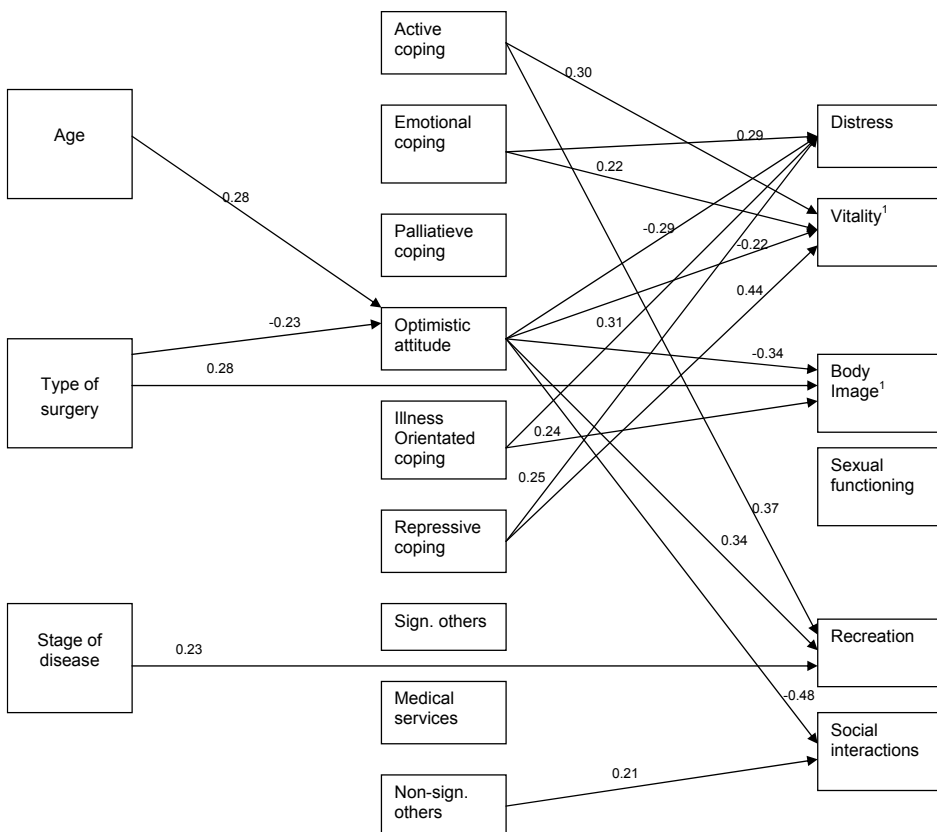


Figure 2: Most plausible model

¹High scores mean worse Vitality and more negative body Image

ated with recreation, in such way that women with a more advanced stage of disease had more problems performing their usual recreational activities. Type of surgery appeared to be directly associated with body image. Women who had a breast conserving therapy, reported to have a more positive body image than those who had had a mastectomy.

Type of surgery was also indirectly associated with several indicators of psychosocial adjustment variables. Women with breast conserving therapy used a more optimistic way of coping. In our study sample, older women also had a more optimistic coping style than younger women. Stage of disease was not associated with any of the coping or social support variables, and, as a consequence, had no indirect association with the psychosocial adjustment variables.

Generic coping

Palliative coping was not associated with any of the psychosocial adjustment outcome variables. Active coping was associated with Vitality and Recreation. In our study group, an active way of coping apparently predicted not only less vitality, but also a reduction in normal recreational activities.

In our model, the use of emotion-focused coping strategies apparently predicted higher distress and less vitality. Generic coping was not associated with psychosexual adjustment.

Illness specific coping

Having an Optimistic Attitude was found to be associated with almost all variables on psychological adjustment. Women with an optimistic attitude felt less distressed and reported more vitality. They also experienced a more positive body image, less reduction in recreational activities and social interactions.

Illness Orientated coping was associated with both Distress and Body Image. Women who were relatively occupied with their illness reported higher distress and a more negative body image.

Finally, women who tend to use repressive coping, reported more distress and less vitality.

Social support

Since the paths between social support and psychosexual adjustment were fixed at zero, no significant associations could be reported between these variables. However, the other paths were not fixed. The only association we found was between getting support from Others and Social Interactions. Women who reported to receive more support from non-significant others, experienced a reduction in social interactions compared to women who did not report getting support from non-significant others.

Discussion

The aim of the study was to identify an empirical-statistical model estimating psychosocial adjustment. The main conclusion is that coping, especially illness specific coping, in our study group was of major importance in estimating psychosocial adjustment. Women who expressed an optimistic way of coping, reported less distress and saw their body as less disfigured than women who did not use optimistic coping strategies. This finding is in line with the results from two other studies [59,60]. However, in these studies optimism was not defined as a coping strategy, but described as a mood state. Optimistic coping was also associated with social adjustment. Women with an optimistic way of coping seemed to be less limited in their recreation activities and social interactions.

As expected, women who were inclined to use an illness orientated coping style showed relatively high levels of distress and reported worse image of their body. This finding is in line with the study of Heim and colleagues (1997) [33], although contradictory to findings of a study by Lavery and co-workers (1996). These authors reported that women who were more anxiously occupied with their illness were better adjusted psychosocially. The mean time since surgery in their study group was nine years after surgery [32], which may partly explain the differences in study results, since time after surgery in our study group was less than one year.

Results for Repressive coping were in the expected direction. Women who used repressive coping showed higher distress, lower vitality and were more limited in their social interactions. These findings confirm results of other studies [61-63].

Some associations between coping style and psychosocial adjustment need further elaboration. An active coping style was associated with recreational activities and experienced vitality. However, both associations were in an unexpected direction. The more active coping was used, the lower vitality was reported and the less one performed usual recreational activities. We suggest, that actively solving problems fires backward: One is confronted with the limitations as a consequence of the illness and becomes aware of not being able to perform the usual activities. The finding that an active way of coping is associated with less vitality is in line with findings from Harrison and Maguire (1994), who reported that in an acute phase of the disease, active coping might result in relatively poorer adjustment [38]. This finding, however, does not imply that emotion-focused coping as opposite to active coping in an acute phase of the disease is positively related to psychological adjustment. As the final model made clear, Emotion-Focused coping was associated with both Distress and Vitality. The more women used an emotion-focused way of coping, the more distress and the less vitality was experienced. These findings confirm results of other studies [32,33,35,37].

A second important finding concerns the role of social support in psychological adjustment to breast cancer. Although other studies convincingly showed a relationship [41-45], we could not confirm this finding in our study, in which several sources of social support were

tested (i.e. support from Significant others, support from Persons from medical services, and support from Others). The only significant association we found, was an association between support from Non-significant others and Social Interactions. The more support one received from others such as colleagues and strangers, the more limitations were experienced in social interactions. This result is not in line with other studies [41-45]. In these studies, the conclusion was that women who received support from family and friends were adjusted more adequately both psychologically [42,43] and socially [41]. Noll Hoskins and co-workers (1996) also concluded that informational support from medical personnel must be maintained to promote positive adjustment [43]. Time of questioning of our sample could be an explanation for not finding any association between social support and psychosocial adjustment. We questioned our women shortly after being diagnosed and operated, a time in which the social network of a woman is usually willing to provide support. It could very well be that when the shock of the diagnosis of breast cancer has gone and for most persons of the social network life has turned normal, social support is more needed by the diagnosed women, while it is not as much provided as in the period just after diagnosis and surgery. We suggest that the role of social support will be more clear some time after diagnosis and surgery.

A third finding concerns the role of biomedical variables in our model. In line with the model used by Schnoll and colleagues (1998) [36], age only had an indirect relationship with psychosocial adjustment. This indirect relationship is mediated by an optimistic coping style. Apparently, younger women tend to use less optimistic coping strategies. This might be explained by the fact that younger women often experience more frequent or severe problems because of their cancer, such as work-problems, financial difficulties, disruption from daily life, unmet needs in child care, and disruption in self-image and sexuality [64, 65].

The expected direct association between Type of surgery on the one hand, and Body Image and Sexual Functioning on the other hand [10,12], was confirmed for Body Image, but not for Sexual Functioning. Women who had breast-conserving therapy, perceived their body as less disfigured than those who had mastectomy. Irrespective of this direct association, the type of surgery was also indirectly associated with psychosocial adjustment, through the use of optimistic coping strategies. Women who had breast-conserving therapy, more often used an optimistic coping style. An explanation is that they perceive their illness as less threatening than women who had mastectomy. Moreover, they do not have to deal with the stresses of having a mutilated body.

Contrary to expectations, we found no association between Type of surgery and sexuality. Results in the literature are mixed, with some authors reporting a clear decline in sexual activity for women who had mastectomy [10,66, 67], while other did not find a difference in sexual functioning between women who had mastectomy and who were treated with breast conserving therapy [15, 68,69]. Reasons for a decline in sexual functioning after breast cancer diagnosis could be the mental status of the diagnosed women [66] or the quality of the relationship of the diagnosed women [15]. A reason for not finding any association

between type of surgery and sexual function could be that the women in our study sample were generally very well psychosocially adjusted at the time of questioning and reported to have relatively healthy relationships.

Findings for Stage of disease were inconclusive. Some authors have reported that stage of disease is related to experiencing more depression and anxiety [13,25], while others have not found such a relationship [26,27]. We did not find any association between Stage of disease and Distress or Vitality. Stage of disease was neither associated with any of the coping and social support variables. However, we did find that women with a more advanced stage of disease reported to be more limited in their recreational activities.

This study had a few limitations. First of all, of the 251 women we contacted, only 87 actually enrolled in this study. We gather that the reason for not participating was because of the fact that it regards an intervention study. The number of non-participants in our study is in line with the number of non-participants of other studies of this kind [65,70]. Studies with higher participation numbers are usually non intervention studies [27,29,32,61] or the study does not described how many patients were approached initially [10,31,34,36]. These last studies give in our opinion an underscore of the real number of eligible patients. We stress, therefore, that the women of our study are representative for women who are diagnosed with breast cancer and are willing to participate in a psychological intervention program.

Because of the relatively small sample size and the relative large numbers of variables, we had to use manifest variables instead of latent variables. This may be considered methodologically as a drawback. Despite these shortcomings, our final model fitted reasonably well.

Another limitation was that in this part of the study, we only tested models cross-sectionally, just after surgery. A longitudinal design will allow for drawing more firm conclusions about causal relationships.

To summarize, the findings indicate that within four months after surgery, coping style, especially illness-specific coping, has high relevance for psychosocial adjustment. Despite findings reported in the literature about the positive role of social support in psychosocial adjustment in women with breast cancer, we could not confirm this association in our study. Age and Type of surgery do have an indirect association with psychological adjustment: Older women and women who had breast conserving therapy tended to use a more optimistic way of coping. Irrespective of that, women who had breast conserving therapy, also reported a more positive body image than their counterparts who had had mastectomy. Finally, women with a more advanced stage of disease reported a reduction in recreational activities.

As coping appears to be a major factor in the psychosocial adjustment to breast cancer, it is a natural conclusion that when women just diagnosed and operated because of breast cancer are offered counseling, this counseling should be focused for a large part on coping with the stresses of being diagnosed with breast cancer. We stress, however, that by only focusing on the use of adaptive coping strategies, other emotional needs could easily be neglected. Intervention programs for women with early stage breast cancer, therefore, should focus on the

experience of having breast cancer, the emotions of being diagnosed with a life-threatening disease and on the coping with the stresses of being diagnosed with breast cancer.

References

1. Kiebert, GM, de Haes, JCJM & van de Velde CJH (1991). The impact of breast conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*, 9: 1059-1070.
2. Fallowfield L (1991). Counselling patients with breast cancer. In Davis H. & Fallowfield L. (Eds). *Counselling and Communication in Health Care*. John Wiley & Sons Ltd, 253-269.
3. Greer S (1994). Psycho-oncology: It aims, achievements and future tasks. *Psycho-Oncology*, 3: 87-101.
4. Spiegel D (1997). Psychosocial aspects of breast cancer treatment. *Seminars in Oncology*, 24: S1-36 - S1-47.
5. Spijker van 't A, Trijsburg RW & Duivenvoorden HJ (1997). Psychological sequale of cancer diagnosis: A meta-analytical review of 58 studies after 1980. *Psychosomatic Medicine*, 59: 280-293.
6. Morris T (1979). Psychological adjustment to mastectomy. *Cancer Treatment Reviews*, 6: 41-61.
7. Hughson AVM, Cooper AF, McArdle CS & Smith DC (1988). Psychosocial consequences of mastectomy, levels of morbidity and associated factors. *Journal of Psychosomatic Research*, 32: 383-391.
8. Goldberg JA, Scott RN, Davidson PM, Murray GD, Stallard S & Maguire GP (1992). Psychological morbidity in the first year after breast surgery. *European Journal of Surgical Oncology*, 18: 327-331.
9. Bleiker EMA, Pouwer F, van der Ploeg HM, Leer JWH & Ader HJ (2000). Psychological distress two years after diagnosis of breast cancer: Frequency and prediction. *Patient Education and Counseling*, 40: 209-217.
10. Margolis G, Goodman RL & Rubin A (1990). Psychological effects of breast conserving treatment and mastectomy. *Psychosomatics*, 31: 33-39.
11. Fallowfield LJ (1995). Assessment of quality of life in breast cancer. *Acta Oncologica*, 34: 689-694.
12. Meyer L & Aspergen K (1989). Long-term psychological sequelae of mastectomy and breast conserving treatment for breast cancer. *Acta Oncologica*, 28: 13-18.
13. Taylor SE, Lichtman RR, Wood JV, Bluming AZ, Dosik GM & Leibowitz RL (1985). Illness-related and treatment related factors in the psychological adjustment to breast cancer. *Cancer*, 55: 2506-2513.
14. Walbroehl GS (1985). Sexuality in cancer patients. *APF*, 31: 153-158.
15. Schover LR (1991). The impact of breast cancer on sexuality, body image and intimate relationships. *CA - A Cancer Journal for Clinicians*, 41: 112-120.
16. Singer Kaplan H (1992). A neglected issue: The sexual side effects of current treatment for breast cancer. *Journal of Sex & Marital Therapy*, 18: 3-19.
17. Anllo LM (2000). Sexual life after breast cancer. *Journal of Sex & Marital Therapy*, 26: 241-248.
18. Fallowfield LJ, Leaity SK, Howell A, Benson S & Cella D (1999). Assessment of quality of life in women undergoing hormonal therapy for breast cancer: Validation of an endocrine symptom subscale for the FACT-B. *Breast Cancer Research and Treatment*, 55: 189-199.
19. Day R, Ganz AA, Costantino JP, Cronin WM, Wickerham L & Fisher B (1999). Health related quality of life and tamoxifen in breast cancer prevention. A report from the National Surgery Adjustment Breast and Bowel project P-1 Study. *Journal of Clinical Oncology*, 17: 2659-2669.
20. Meyerowitz BE (1980). Psychosocial correlates of breast cancer and its treatment. *Psychological Bulletin*, 87: 108-131.
21. Andersen BI, Anderson B & deProse C (1989). Controlled prospective longitudinal study of women with breast cancer: II Psychological outcomes. *Journal of Consulting and Clinical Psychology*, 57: 692-697.
22. Maunsell E, Brisson C, Dubois L, Lauzier S & Frazer A (1999). Work problems after breast cancer: An exploratory qualitative study. *Psycho-Oncology*, 8: 467-473.
23. Polinsky ML (1994). Functional status of long-term breast cancer survivors: Demonstrating chronicity. *Health & Social Work*, 19: 165-173.
24. Schottenfeld D & Robbins GF (1970). Quality of survival among patients who have had radical mastectomy. *Cancer*, 26: 650-654.

25. Vinokur AD, Threatt BA, Caplan RD & Zimmerman BL (1989). Physical and psychosocial functioning and adjustment to breast cancer. Long-term follow-up of a screening population. *Cancer*, 63: 394-405.
26. Lansky SB, List MA, Herrmann CA, Ets Hokin EG, DasGupta TK, Wilbanks GD & Hendrickson FR (1985). Absence of major depression disorder in female cancer patients. *Journal of Clinical Oncology*, 3: 1553-1560.
27. Hopwood P, Howell A & Maguire P (1991). Psychiatric morbidity in patients with advanced cancer of the breast: prevalence measured by two self-rating questionnaires. *British Journal of Cancer*, 64: 349-352.
28. Irvine D, Brown B, Crooks D, Roberts J & Browne G (1991). Psychosocial adjustment in women with breast cancer. *Cancer*, 15: 1097-1117.
29. Vinokur AD, Threatt BA, Vinokur-Kaplan D & Satariano WA (1990). The process of recovery from breast cancer for younger and older patients. Changes during the first year. *Cancer*, 65: 1242-1254.
30. Felton BJ & Revenson TA (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology*, 52: 343-353.
31. Fawzy IF, Cousins N, Fawzy NW, Kemeny ME, Elashoff R & Morton D (1990). A structured psychiatric intervention for cancer patients. I. Changes over time in methods of coping and affective disturbance. *Archives of General of Psychiatry*, 47: 720-725.
32. Lavery JF & Clarke VA (1996). Causal attributions, coping strategies, and adjustment to breast cancer. *Cancer Nursing*, 19: 20-28.
33. Heim E, Valach L & Schaffner L (1997). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. *Psychosomatic Medicine*, 59: 408-418.
34. Carver CS, Pozo C, Harris SD, Noriega V, Scheier MF, Robinson DS, Ketchman AS, Moffat FL & Clark KC (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65: 375-390.
35. Miller DL, Manne SL, Taylor K, Keates J & Dougherty J (1996). Psychological distress and well-being in advanced cancer: The effects of optimism and coping. *Journal of Clinical Psychology in Medical Settings*, 3: 115-130.
36. Schnoll RA, Harlow LL, Stolbach LL & Brandt U (1998). A structural model of the relationships among stage of disease, age, coping, and psychological adjustment in women with breast cancer. *Psycho-Oncology*, 7: 69-77.
37. McCaul KD, Sandgren AK, King B, O'Donnell S, Branstetter A & Foreman G (1999). Coping and adjustment to breast cancer. *Psycho-Oncology*, 8: 230-238.
38. Harrison J & Maguire P (1994). Predictors of psychiatric morbidity in cancer patients. *British Journal of Psychiatry*, 65: 593-598.
39. Carver CS, Scheier MF & Weintraub JR (1989). Assessing coping strategies: A theoretical based approach. *Journal of Personality and Social Psychology*, 56: 267-283.
40. Wool MS (1988) Understanding denial in cancer patients. *Advances in Psychosomatic Medicine*, 18: 37-53.
41. Bloom JR & Spiegel D (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning with advanced breast cancer. *Social Science and Medicine*, 19: 831-837.
42. Lichtman RR, Taylor SE & Wood JV (1987). Social support and marital adjustment to breast cancer. *Journal of Psychosocial Oncology*, 5: 47-74.
43. Noll Hoskins C, Baker S, Sherman D, Bolander C & Maisin G (1996). Social support and patterns of adjustment to breast cancer. *Scholarly Inquiry for Nursing Practice: An International Journal*, 10: 99-123.
44. Smyth MM, McCaughan E & Harrison S (1995). Women's perception of their experiences with breast cancer: are their needs being addressed? *European Journal of Cancer Care*, 4: 86-92.
45. Spiegel D & Kato PM (1996). Psychological influences on cancer incidence and progression. *Harvard Rev Psychiatry*, 4: 10-26.

46. Schreurs PJG, van de Willige G, Brosschat JF, Tellegen B & Graus, GMH (1993). *De Utrechtse Coping Lijst. Omgaan met Problemen en Gebeurtenissen. Herziene Handleiding*. Swets & Zeitlinger B.V.: Lisse, The Netherlands.
47. de Bruin EJ & van Dijk M (1996). *Health and Disease Inventories. Een meetinstrument voor Aanpassingen aan Kanker. Handleiding*. Swets & Zeitlinger B.V., Lisse and Helen Dowling Instituut, Rotterdam, The Netherlands.
48. de Haes JCJM (1988). *Kwaliteit van leven van kankerpatiënten*. Dissertation, Rijksuniversiteit Leiden, Lisse Swets & Zeitlinger: The Netherlands.
49. de Groot MH (1991). Psychometrische aspecten van een stemmingsschaal (verkorte POMS). *Gedrag en Gezondheid*, 20: 46-51.
50. Sprangers MAG, Groenvold M, Arraras JI, Franklin J, te Velde A, Muller M, Franzini L, Williams A, de Haes HCJM, Hopwood P, Cull A & Aaronson NK (1996). The EORTC Breast Cancer-Specific Quality of Life Module (QLQ-BR32): first results from a three-country field study. *Journal of Clinical Oncology*, 14: 2756-2768.
51. Osoba D, Aaronson N, Zee B, Sprangers M & te Velde A (1997). Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. *Quality of Life Research*, 6: 103-108.
52. Bergner M, Bobbit RA, Carter WB & Gilson BS (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19: 787-805.
53. Hair JF. jr, Anderson RE, Tatham RL & Black WC (1998). *Multivariate Data Analysis. Fifth Edition*. Prentice-Hall Inc: New Jersey, USA.
54. Hoyle RH & Smith GT (1994). Formulating clinical research hypotheses as structural equation models: A conceptual overview. *Journal of Consulting and Clinical Psychology*, 62: 429-440.
55. Muthén LK & Muthén BO (1998) *Mplus. User's Guide*. CA Muthén & Muthén: Los Angeles.
56. Bentler PM. (1990). Comparative fit indexes in structural models. *Psychological Bulletin*, 107: 238-246.
57. Tucker LR & Lewis C (1973). A reliability coefficient for maximum likelihood factor analysis. *Psychometrika*, 38: 1-10.
58. Steiger JH (1990). Structural model evaluation and modification: An interval estimation approach. *Multivariate Behavioral Research*, 25: 173-180.
59. Stanton AL & Snider PR (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology*, 12: 16-23.
60. Weisman AD & Worden JW (1976-1977). The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*, 7: 1-15.
61. Watson M, Greer S, Rowden L, Gorman C, Robertson B, Bliss JM & Tunmore R (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological Medicine*, 21: 51-57.
62. Classen C, Koopman C, Angell K & Spiegel D (1996). Coping styles associated with psychological adjustment to advanced breast cancer. *Health Psychology*, 15: 434-437.
63. Auchincloss S (1991). Sexual dysfunction after cancer treatment. *Journal of Psychosocial Oncology*, 16: 23-41.
64. Ganz PA, Coscarelli Schag C & Heinrich R (1985). The psychosocial impact of cancer on the elderly. A comparison with younger patients. *Journal of American Geriatric Society*, 33: 429-435.
65. Dunn J & Steginga SK (2000). Young women's experience of breast cancer: Defining young and identifying concerns. *Psycho-Oncology*, 9: 137-146.
66. Dobkin PL & Bradley I (1991) Assessment of sexual dysfunction in oncology patients: Review, critique, and suggestions. *Journal of Psychosocial Oncology*, 9: 43-73.
67. Pozo C, Carver CS, Noriega V, Harris SD, Robinson DS, Ketcham AS, Legaspi A, Moffat FL & Clark KC (1992). Effects of mastectomy versus lumpectomy on emotional adjustment to breast cancer: A prospective study of the first year postsurgery. *Journal of Clinical Oncology*, 10: 1292-1298.
68. Wellisch DK, DiMatteo R, Silverstein M, Landsverk J, Hoffman R, Waisman J, Handel N, Waisman-Smith E & Schain W (1989). Psychosocial outcomes of breast cancer therapies. Lumpectomy versus mastectomy. *Psychosomatics*, 30: 365-373.

69. Lee MS, Love SB, Mitchell JB, Parker EM, Rubens RD, Watson JP, Fentiman IS & Haward, JL (1992). Mastectomy or conservation for early stage breast cancer: Psychological morbidity. *European Journal of Cancer*, 8/9: 1340-1344.
70. Cunningham AJ, Edmonds CVI, Jenkins GP, Pollack GP, Lockwood GA & Warr D (1998). A randomised controlled trial of the effects of group psychological therapy on survival in women with metastatic breast cancer. *Psycho-Oncology*, 7: 508-517.

3

Psychosocial intervention for women with primary, non-metastatic breast cancer: A comparison between participants and non-participants

Petra J. Vos

Bert Garssen

Adriaan P. Visser

Hugo J. Duivenvoorden

Hanneke C.J.M. de Haes

Abstract

Despite improvements in medical treatment for breast cancer, resulting in better prognoses, women diagnosed with the illness often experience psychosocial problems. As a result, many psychosocial intervention programs have been developed, usually with positive results. The aim of this study was to examine the effects of two 12-week psychosocial intervention programs for women with a primary, non-metastatic breast cancer diagnosis, compared to women who were on a waiting-list for these interventions for three months.

Sixty-nine women with primary, non-metastatic breast cancer, but otherwise without psychosocial problems, were randomised into a group intervention program (group psychotherapy or social support group) or a waiting-list control group. Differences between both groups in psychosocial adjustment, social support and coping at short-term were described in this study.

Women who participated in the group intervention programs did not differ from women in the waiting-list control group on psychosocial adjustment at the end of the study. Women who participated in the social support groups, reported to receive more social support from others not very close to them. They also used more palliative coping than women from the group psychotherapy.

Apparently, at short-term, women who are being diagnosed with breast cancer, but otherwise have no psychosocial adjustment problems after diagnosis, do not especially benefit from an intervention program at short-term, compared to women who were in a waiting-list control group.

Introduction

Medical treatment of breast cancer has improved significantly in the past decades [1,2] and consequently patients with breast cancer live longer, especially when diagnosed at an early stage [3]. Yet, being diagnosed with breast cancer is still seen as a life-threatening event and is often accompanied with psychosocial problems, especially distress (anxiety, depression), sexual and body image problems, and difficulties in social relations [4-6]. Many psychosocial intervention programs have been developed and tested to help cancer patients cope with these problems [7-9]. Most studies have found that these psychosocial interventions lead to a reduction of distress and improvement in coping abilities [7-13]. However, when the study samples were divided into patients who were more at risk for developing psychological problems and patients who were not, it appeared that especially patients who were at risk contributed to the significant positive changes in psychological distress [10-13].

Since coping style has an important influence on well-being in women suffering from breast cancer, many intervention programs encompass at least some elements of coping skill training [14,15-20]. Two studies among women with breast cancer [17,20], in which coping skill training was an important element in the intervention, report positive effects on distress, social functioning [17,20], quality of life [17], and physical health [20]. Results were enhanced three [17] and six months [20] later. Another study in which a cognitive behavior therapy for women with metastatic breast cancer was compared to a no treatment condition, showed less convincing treatment effects: Although participants showed less depression and less total mood disturbance, and improved self-esteem shortly after the intervention, these differences disappeared at three and six months follow-up [19].

In the abovementioned studies, it is, however, unclear whether coping abilities changed as well. Spiegel and colleagues [14] reported that women participating in psychological supportive group psychotherapy reported positive changes with respect to vigour and fatigue. These women also used less maladaptive coping strategies compared to women of a non-intervention control group. Another study among breast cancer patients [18] also found a positive intervention effect on maladaptive coping. These studies indicate that participating in a group intervention usually leads to the use of more effective coping, especially if the intervention includes a coping skill training.

Another important factor in adjustment to breast cancer is receiving social support. Patients, suffering from a serious disease such as breast cancer, who receive adequate social support, are better adjusted psychologically, experience a greater sense of well-being and are less depressed than patients who do not receive social support or when the social support they receive is perceived as inadequate [6,18,21-23]. Social support is also an important focus in group intervention programs [6,7,24]. Participating in a group intervention program gives patients the opportunity to share feelings with other patients who function as a social support source. Therefore, one may expect a positive effect on psychosocial adjustment. Results

of intervention studies on social support, however, are mixed. In a study of Samarel and colleagues [25] a significant improvement in the quality of relations with significant others was found just after the intervention. This effect was not maintained at eight weeks follow-up. Helgeson and co-workers [26] reported that women who participated in a peer-discussion intervention condition and were at the start of the intervention satisfied with the emotional support, deteriorated. However, those who at the start of the intervention lacked emotional support or had more negative interactions with their partners, benefited from the peer-discussion group. Participants of the education groups reported a positive effect, which was strongest for women who reported lack of emotional and informational support at the start of the intervention. Other group intervention studies [6,27-29] did not find improvements in levels of social support, suggesting that participating in a group is not necessarily beneficial with respect to social support.

In the present study, women with primary, non-metastatic breast cancer were randomised into a group intervention condition (either a group psychotherapy condition or a social support group condition), or a waiting-list control group condition. This study is part of a long-term intervention study, and women who were in the waiting-list control group condition, were randomised in one of the intervention conditions after three months. In this part of the study, we describe the post-treatment differences between participators and non-participators of the intervention at short-term, with respect to psychosocial adjustment (i.e. psychological, psychosexual and social adjustment), coping and social support. We expect that women who participated in a group intervention program will show some improvement in psychosocial adjustment. We suggest that they have changed their way of coping in case it was maladaptive and are better able to get the social support they want compared to women in the waiting-list control group condition. Finally, we also studied whether effects on psychological, psychosexual and social adjustment were mediated by coping and perceived social support.

Methods

Subjects and procedures

Patients were recruited from several hospitals in the region of Rotterdam, The Netherlands. Eligible participants were women between 18 and 70 years of age, who had had surgery for primary breast cancer no longer than four months ago, no distant metastases, sufficient knowledge of the Dutch language, and no psychiatric illness. They were informed about the study by an oncology nurse, who also judged the absence of psychiatric illness. Women were told that they were not offered a choice, but were randomly allocated to one of four conditions after completion of the first questionnaire: Early start or after a waiting period of several months; psychotherapy group or social support group. If a woman was not motivated

to participate, she could indicate this by returning an answering-form. If not returned within three weeks, the investigator attempted to contact the women by telephone, asking patients to participate. If they consented, an appointment was made for the first interview, in which women were asked to sign a written informed consent and a set of questionnaires was handed over. Women were asked to complete these questionnaires at their earliest convenience and return them by mail. After receiving the questionnaires, patients were randomised into the waiting-list control group, the group psychotherapy or the social support group.

The second measurement (T2) was planned about three months later. For the women who participated in a group intervention, this was just after having completed the intervention, while for those in the waiting-list control group it was just before the start of the intervention.

Measures

Medical and demographic data were obtained from a general questionnaire containing anamnestic questions (size of tumour, date of diagnosis and surgery, type of surgery, number of affected lymph nodes, adjuvant therapy) and demographic questions (age, education, marital status, work status). The referring oncology nurse checked the information in medical records for women who agreed to participate.

Coping was assessed with two questionnaires. Generic coping was measured with shortened 19-item version of the Utrecht Coping List (UCL) [30]. It covers three dimensions of coping: 1) Active coping ($\alpha = 0.83$), 2) Emotion Focused coping ($\alpha = 0.75$), and 3) Palliative coping ($\alpha = 0.70$). Higher scores represent a more frequent use of that particular coping strategy [30].

Illness specific coping was measured with the Health and Diseases Inventories (HDI), designed especially for cancer patients [31]. It consists of three subscales: 1) Optimistic Attitudes ($\alpha = 0.74$): Persons who score high on this subscale have a self-confident and optimistic attitude toward life, they enjoy life and have confidence in the future, they also act as if nothing has happened; 2) Illness Orientated coping ($\alpha = 0.65$): Indicating a preoccupation with what is happening in one's body and fostering a negative, fatalistic idea about the disease. 3) Repressive coping ($\alpha = 0.85$): Non-expression of negative emotions, and asking for support and attention of others.

Social support was measured with the Social Network Questionnaire (SNQ) [32], concerning the following dimensions: 1) Significant others, such as partner, family and close friends ($\alpha = 0.43$), 2) Persons from the medical setting, such as doctors and other medical personnel ($\alpha = 0.65$), and 3) Others, such as psychosocial workers, colleagues and strangers ($\alpha = 0.14$).

Psychosocial adjustment was covered by three scales:

Emotional adjustment was measured with the Dutch version of the Profile of Mood States (POMS) [33], which measures mood states in five areas: Depression ($\alpha = 0.89$), Anger ($\alpha = 0.91$), Fatigue ($\alpha = 0.91$), Tension ($\alpha = 0.89$), and Vigour ($\alpha = 0.80$). A higher score indicates that a particular mood is more often experienced [33].

Psychosexual functioning was measured with the subscales Sexual Functioning ($\alpha = 0.81$) and Body Image ($\alpha = 0.89$) of the breast cancer specific module (QLQ-BR32) [34] of the EORTC QLQ-30 [35]. It includes questions about side effects of different treatment modalities, body image and sexuality. Higher scores on the subscales Sexual Functioning and Body Image represent a better level of functioning [34].

Social adjustment was measured with the subscales Social Interactions ($\alpha = 0.75$) and Recreation ($\alpha = 0.75$) of the Sickness Impact Profile (SIP) [36]. This is a daily functioning questionnaire, which describes the impact of illness on behavior in twelve dimensions. Higher scores represent more impact of the illness.

Reliability and validity of all used questionnaires are adequate for the Dutch population.

All data were collected at T1 and T2, with the exception of coping measures. Coping questionnaires were only included in the T2 measurements of the intervention groups, not of the waiting-list control group.

Interventions

The psychotherapy group program has been tailored to the specific emotional, sexual and social needs of post-surgical breast cancer patients. It is based on Experiential-Existential (EE) premises [37] enriched with Cognitive Behavioral (CB) components and was developed for this study on the basis of long-term experience in group-interventions for patients with cancer at the Helen Dowling Institute. The existential approach means that the psychotherapeutic counseling focus on a stimulation of exploration of personal needs, problems and personal strength. From this point, solutions for personal problems are sought. In this process, the emphasis is on the potential personal growth and need to develop. The methods used in this counseling were taken from the CB approach. The program was semi-structured, in a sense that the topics and goals of the intervention were outlined in a manual [38], which served as a practical guide for the therapists. The timing of realisation of the basic goals of the sessions was decided by the clinical judgement of the therapists. Topics for the 12 sessions were established in advance (see Box 1), but the group members themselves determined for each session which of these topics they wanted to discuss. The therapists had to make sure that all the topics were dealt with during the 12 sessions. The main aim of the psychotherapy group was that participants learnt how they felt about having breast cancer and the consequences of it and how to learn to express these feelings.

The social support groups were designed to let breast cancer patients share their mutual experiences with respect to the diagnosis and treatment for breast cancer. Patients were encouraged to use the group to obtain peer support and emotional encouragement. A treatment manual was not developed for this type of intervention. There were, however, certain rules group members had to follow (rules about safety, speaking for oneself) and the sessions were structured: All sessions started with a round in which members told about the past week. Next they discussed the subject they choose the previous week. This part was split

Box 1: Topics to be discussed in intervention

Topics which should be discussed in both group interventions
<p>First session:</p> <ul style="list-style-type: none"> - Introduction - Rules of the group - Feeling safe in the group <p>All other sessions:</p> <ul style="list-style-type: none"> - Personal meaning of having (had) cancer - Fear of recurrence - Coping with feelings of uncertainty and control - Coping with emotions - Self image - Body image - Sexuality - Intimacy - Asking for social support - Giving social support - Coping with the partner - Coping with other relatives - Coping with the past - Saying goodbye/farewell - Holding on to changes - Going on without going to 'the group'

by a short coffee break. At the end of the session, members choose the subject for the next session. Although group members could choose themselves which topic they wanted to discuss in the next session, they had to choose it from a number of selected topics (see Box 1). The main aim of this intervention was to learn to cope in a practical manner with problems women experience as a consequence of having breast cancer.

Both intervention conditions consisted of 12 weekly sessions of 2,5 hours. After the regular sessions, two additional sessions followed at respectively one and two months.

Statistical analyses

Because of the high ratio between dependent variables and the number of participants, we limited the number of variables in the analyses. Intercorrelation coefficients were estimated for the six subscales of the coping measures (UCL and HDI) and the subscales of the POMS. In case of sufficient intercorrelations, principal component analyses were performed on the subscales of the coping subscales and the POMS, respectively. This procedure was described in more detail elsewhere [39].

Differences between the groups with regard to demographic and medical variables and baseline values of psychosocial adjustment, social support and coping were tested with univariate analyses of variance (ANOVA) for the continuous data and χ^2 analyses for ordinal data.

To discriminate between the intervention group condition and the waiting-list control group condition, the variable 'Group' was coded as 1 for participation in the intervention condition and 0 for being in the waiting-list control group condition. As we were also interested in the

differences between type of interventions, the variables 'Therapy' was coded 1 for having participated in the group psychotherapy intervention and 0 for participating in the social support groups or being in the waiting-list control group. The variable 'Support' was coded 1 for participating in the social support group condition and 0 for being allocated to the group psychotherapy program or being in the waiting-list control group.

Multiple regression analysis was used to test for the effects of the psychosocial interventions compared to being on the waiting-list on post intervention outcome measures (psychosocial adjustment, social support and coping), taking into account the baseline values (T1) thereof [40]. To gain insight into the relative importance of each predictor, the standardized regression coefficient (β) was used. The statistical level of significance was fixed at $p \leq 0.05$, two-tailed. The variance inflation factor (VIF) values (an index of multicollinearity) had to be smaller than 4 [41]. Moreover, a regression model was considered plausible if the predictor variables and the interaction terms were statistically significant, provided that the VIF-values were within acceptable limits.

The sequence of regression analyses was as follows. In the first series of regression analyses, the model consisted of the baseline values, corresponding to the outcome variable, and the variable 'Group'. In the second step social support and coping variables, measured at baseline (T1), and demographic variables (i.e. Age, Stage of disease and Type of surgery) were added in the regression analyses.

In case of a significant difference between women participating in any of the intervention group programs and women in the waiting-list control group condition, the regression analyses were performed again, replacing 'Group' by 'Therapy' and 'Support'. This way we were able to determine whether the effect was due to participating in one group especially.

The same steps were applied to test the effects of the intervention on coping. However, since coping was only assessed at T2 among women who participated in any of the intervention groups, the variable 'Group' was replaced by the variable 'Type of intervention'.

Results

Sample description

Two hundred and fifty one eligible women were contacted by the investigators by telephone. The reasons for not participating of 164 women were: 1) not interested (15.9%), 2) having enough support (15.9%), 3) being too emotionally distressed (8.5%), 4) could not be reached by telephone (11.6%), 5) other reasons such as distance and time (16.5%), and 6) unknown (32.5%). Of the remaining 87 women (34.7%), 69 completed this part of the study at T2. Of the 18 women who dropped out, one women had died, for one women going to a group became too emotional, three women were too ill to attend group meetings, for one woman the group meetings were not what she had expected, twelve women stopped their participation

without giving a reason. Women who stopped participating, did not differ on medical and demographic variables from the participants who stayed in the study. However, at baseline they reported receiving significantly less social support from Others, such as colleagues and neighbours ($p = 0.05$) than women who participated.

Of the 69 participants, no woman had distant metastases, but 20 women had affected lymph nodes (N₁). Most participating women had had a mastectomy (66.7%). Only three of them had had a reconstruction at the time of interview. The mean age was 49.2 years (range 29-68; SD 7.90). Most women had finished secondary school as their highest education (68.1%), and had a partner (73.9%). Seven of them were not living with their partner. Of the 16 single women, 3 were never married, 11 women were divorced and 2 women were widowed. Medical and demographic data are summarized in Table 1. The women in our study did not differ on mental health status from the general healthy population.

Of the 69 women 34 women were assigned to the group intervention programs --15 of them participated in the group psychotherapy condition and 19 in the social support group condi-

Table 1: Medical and demographic characteristics

	No.	%
Total patients	69	100
Time since surgery (weeks)		
Mean (range)		9.25 (3-16)
Stage		
0	3	4.3
I	24	34.8
II	33	47.8
III	3	4.3
Missing	6	8.7
Number of affected lymph nodes		
0	48	69.6
1-4	15	21.7
>4	5	7.2
Missing	1	1.5
Type of surgery		
Breast conserving therapy	23	33.3
Mastectomy	46	66.7
Age (years)		
Mean (range)		49.2 (29-68)
Highest education		
Primary school	5	7.2
Secondary school	47	68.1
Higher education	14	20.3
Missing	3	4.3
Marital status		
Partner	51	73.9
Single	16	23.2
Missing	2	2.9

tion -- while the other 35 participants were in the waiting-list control group condition. For those who were in the group intervention, the mean time between T1 and T2 was 21 weeks, while for those who were in the waiting-list control group this was 16 weeks. This difference was not significant. Women who took part in the group psychotherapy condition did not differ on medical and demographic variables or on the baseline measures of psychosocial adjustment, social support and coping from those who participated in the social support group condition. Participants of the intervention group conditions did neither differ from women in the waiting-list control group condition on any of the abovementioned variables.

Data reduction

Pearson correlation-coefficients were determined for the six coping subscales and the subscales of the POMS. The coping subscales appeared relatively independent and, consequently, data-reduction would yield too much loss of information. Intercorrelations of the POMS-subscales were all statistically significant, with the lowest correlation being $r = 0.35$ for the subscales Vigour and Tension. A principal component analysis with Varimax rotation was performed on the subscales of the POMS, which resulted in two separate factors. The first component represents 'Distress' and is formed by the subscales Depression, Anger and Tension. The second component is formed by the subscales Vigour and (reverse of) Fatigue and represents 'Vitality'. For both components, the means of the composing subscales were summarized and used in the analyses.

Intervention effects on psychosocial adjustment

Of the regression models that have been tested, several models appeared to be multicollinear and, as a result, were eliminated. Of the models left, only models that included the highest number of predicting variables for each outcome variable, are presented in Table 2.

As can be concluded from Table 2, all outcome variables were predicted by the baseline levels of the corresponding variables: A higher level at T1 predicted a higher level of the same variable at T2. The variable 'Group' was not predictive for any of the outcome variables. Apparently, participating in a group intervention or being in a waiting-list control group did not influence the outcome at T2.

Distress at T2 was predicted by Illness Orientated coping. Women, who had a high level of Illness Orientated coping at the start of the study, reported more Distress at T2 ($p=0.03$). Age was predictive for Sexual Functioning ($p=0.03$). Older women had fewer problems with sexual functioning at T2 than their younger counterparts. Finally, Social Interactions were also predicted by coping. Women who reported a more emotion focused way of coping at baseline, were less limited in their social interactions at T2 ($p=0.05$), while women who had a palliative coping style, reported more restrictions in their social interactions at that time ($p=0.02$).

Table 2: Results of regression analyses of psychosocial adjustment

	Distress	Vitality	Body Image	Sexual Functioning	Social Interactions
Corresponding value at T1 β	0.36*	0.59**	0.80**	0.65**	0.84**
Group β	-0.13	-0.13	-0.05	-0.17	0.08
Age β	-0.13	-0.11	-0.00	0.28*	0.16
Stage of disease β	-0.04	0.07	0.07	0.08	0.11
Type of surgery β	-0.09	0.07	-0.05	0.07	-0.14
Active coping β	-0.13	0.23	-0.06	-0.22	-0.03
Emotion focused coping β	-0.08	0.10	0.05	0.17	-0.29*
Palliative coping β	0.05	-0.06	0.07	-0.10	0.24*
Optimistic coping β	0.04	0.13	-0.15	-0.08	0.17
Illness Orientated coping β	0.42*	-0.24	-0.17	-0.08	0.24
Repressive coping β	-0.05	0.24	0.04	0.04	-0.06
Support sig. Others β	-0.02	-0.16	0.05	0.01	0.02
Support Med. Services β	-0.01	-0.14	0.15	0.06	-0.15
Support Others β	-0.16	0.07	0.04	0.01	-0.03
R ²	0.51	0.45	0.73	0.57	0.64

* $p < 0.05$ ** $p < 0.01$ *Intervention effects on social support*

As for psychosocial adjustment, several models appeared to be multicollinear and were thus eliminated. Models with the most predictive value are presented in Table 3.

For all social support outcome variables, their baseline levels predicted outcome at T2: The higher the levels were at baseline, the more support was perceived at follow-up. Women who participated in the intervention groups perceived at the end of treatment more support from Others than women on the waiting list ($p=0.01$). Stage of disease was predictive for

Table 3: Results of regression analyses on social support

	Support Sig. Others	Support Med. Services	Support Others
Corresponding value at T1 β	0.63**	0.47*	0.55**
Group β	0.03	-0.18	-0.31**
Age β	0.02	-0.09	0.15
Stage of disease β	0.31**	-0.02	0.35*
Type of surgery β	-0.19	-0.03	-0.17
Active coping β	0.01	0.12	-0.06
Emotion focused coping β	-0.20	0.11	-0.01
Palliative coping β	0.04	-0.23	0.15
Optimistic coping β	0.33**	0.01	0.12
Illness Orientated coping β	0.13	-0.22	0.24
Repressive coping β	-0.24	0.08	-0.09
R ²	0.64	0.29	0.48

* $p < 0.05$ ** $p < 0.01$

support gained from Others ($p \leq 0.01$) and from Significant Others ($p \leq 0.01$). Women with a more advanced stage of disease perceived more support from both groups. Women with an optimistic attitude, also reported to gain more support from significant others than women with a less optimistic attitude.

To determine whether the influence of participating in a group on support from non-significant others was due to participation in the group psychotherapy, the social support group or both, a regression analysis was performed in which 'Group' was replaced by the variables 'Therapy' and 'Support'. It appeared that women who participated in the social support groups, perceived at the end of treatment more support from Others than their counterparts, who had participated in the group psychotherapy program or were in the waiting-list control group ($p \leq 0.01$).

Intervention effects on coping

Also for coping, several models were multicollinear and were eliminated. Models with most predictive value are summarized in Table 4.

Levels at baseline were predictive for level of Active coping, Emotion Focused coping, Optimistic Attitude and Illness Orientated Coping at T2: More use of these kinds of coping at baseline, meant that these coping types also were more used at T2. For Palliative coping and Repressive coping, the predictions were not statistically significant. For Palliative coping, it appeared that participating in the social support group, predicted more use of Palliative coping at T2 ($p = 0.05$). Social support from significant others at baseline, appeared to be predictive for Emotion focused coping at T2 ($p = 0.04$). Women who received more support from significant others, use more often an emotion focused way of coping at T2. Social support from Others seem to lead to more Repressive coping ($p = 0.02$).

Table 4: Results of regression analyses on coping

	Active coping	Emotion focused coping	Palliative coping	Optimistic Attitude	Illness Orientated coping	Repressive coping
Corresponding value at T1 β	0.67**	0.37*	0.39	0.67*	0.81**	0.29
Group β	0.03	-0.18	-0.45*	-0.06	-0.20	0.06
Age β	0.03	0.07	-0.11	-0.05	0.08	0.15
Stage of disease β	0.24	0.33	0.04	0.34*	-0.15	-0.12
Type of surgery β	-0.16	-0.21	-0.35	-0.17	-0.07	0.13
Support sig. Others β	-0.22	0.36*	-0.32	0.09	-0.15	-0.01
Support Med. Services β	-0.11	-0.32	0.28	0.07	-0.16	0.03
Support Others β	0.11	0.08	0.20	-0.04	0.03	0.55*
R ²	0.52	0.58	0.43	0.71	0.69	0.56

* $p < 0.05$

** $p < 0.01$

Discussion

The aim of the present study was to test whether participating in a group intervention program was effective in psychosocial adjustment and social support by comparing the intervention condition by a waiting list condition, in a randomised study. A second aim was to test whether coping would change after participating in a group intervention program. Several conclusions can be drawn from this study. First of all, no differences in psychosocial adjustment were found at T2 between the women who participated in the group interventions and women who were in the waiting-list control group. A second finding was that women in the intervention group condition experienced more support from Others than women in the waiting-list control group condition. No differences were found for Support from significant others and Support from medical services. It appeared that especially those women who participated in the social support groups report more support from Others. A final result concerns coping: The kind of intervention women participated in did not predict coping patterns at the end of treatment, with exception of Palliative coping. Women in the social support groups used more palliative coping than women in the group psychotherapy condition.

These findings are in line with those of Tarrier and Maguire [42], who did neither find a reduction in psychosocial adjustment at the end of psychosocial treatment, and findings of Berglund and colleagues [43], who even report a negative effect on coping after participating in a group intervention. However, our findings seem to be in contradiction with most other studies [10-17,27,44,45]. These studies show positive effects of an intervention program on psychosocial adjustment and coping compared to no psychosocial treatment, although in some studies the positive changes were mainly contributed to at-risk patients [10-13].

A closer look at these studies reveals, however, that our findings may not be uncommon, especially with respect to social support groups. For instance, in several studies [15,27,46,47] the participants of the social support groups did not differ on psychosocial adjustment from the patients in the control group. In these studies, only the participants of the Cognitive Behavioral Therapy group [27], the Coping Skills Group [15] and the educational groups [46,47], reported significant improvements just after completion of the intervention. We, on the other hand, did not only find no treatment effect in the social support groups, but neither in the group psychotherapy, which was a rather unexpected result.

In our study, we only concentrated on short-term effects. It was not possible to study long-term effects, while after being on the waiting list for about three months, women in this condition also started with one of the two group intervention programs. It may very well be that findings at follow-up would be different. Some studies did find positive effects of participating in an intervention just after completion, but these effects disappeared at follow-up some months later [27]. In other studies, however, the effects just after completion of the intervention were absent [42] or rather small [16,44], while at follow-up some months later,

those participating in a group intervention program were significantly better adjusted than patients of the non-intervention control group.

An explanation for these discrepancies in findings could be the type of patients who were studied. Our study sample consisted of women who were approached actively to participate in this study. Most of these women were mentally healthy, which was not always the case in other intervention studies [27,42,45]. Most of the women in our study would not have sought psychosocial counseling in case it was not offered. However, about one third of the women stated that they participated to help themselves. Apparently, the other women were at the start of the intervention not as motivated as participants of self referred intervention studies. Finally, we were only able to study the short-term effects of intervention for ethical reasons. It was thought unethical to withhold women from psychosocial counseling for longer than three months.

The coping style at the start of the study appeared to be predictive for some psychosocial adjustment. Using emotion focused coping leads in this sample to more social interactions at the end of treatment, while a palliative coping style predicts a reduction in social interactions. Illness specific coping was predictive for both psychosocial adjustment and social support. Having an illness orientated coping style leads to more distress at T2, but also to more support from people less close to the patients. Women who expressed an optimistic attitude about their illness, experiences more support from more significant others.

Finally, some of the demographic variables were predictive for psychosocial adjustment, social support and coping variables. Being younger predicted more problems with sexual functioning. We could, however not support conclusions from other studies [48-50] that younger women were less psychologically adapted than their older counterparts. In our study, older patients tend to use more repressive coping, meaning that they did not express their feelings as much as younger patients did, which is in line with findings of Schnoll and colleagues [51].

Stage of the disease was predictive of the amount of support one receives: Being diagnosed with a more advanced stage of disease leads to more support from both significant others and from persons who are less close to the patients. Although not confirmed in our study, this could be the result of having somewhat better coping strategies when having a more advanced stage of disease, as was reported by Schnoll and co-workers [51].

Generally, we may conclude that in this study participating in a group intervention is no more effective than being in a waiting-list control group condition, at least not at short-term. Only the women who participated in a social support group report more social support from persons at some distance compared to women who were in the waiting-list control group or who participated in a group psychotherapy. Women in the social support groups, also used a more palliative way of coping at the end of their treatment than did women in the group psychotherapy.

A limitation of this study could be the number of participating women, the mental state of the participating women and the motivation for participation. In this study, only 27.5% of all approached women participated. Although this is not a large number, it confirms what is reported in other randomised intervention studies, which fully describe the number of eligible patients and the number of patients who completed the study [28,52,53]. Randomised studies with higher numbers usually not describe how many eligible patients were sent a letter for participation or how many eligible patients were reached by other means [11,14,17,25]. These studies give, in our opinion, an underscore of the real number of eligible patients. We stress, therefore, that the women of our study are representative for women who are diagnosed with breast cancer and are willing to participate in a psychological intervention program. Women in the present study were mentally just as healthy as persons from the general population. This could be considered as a drawback, but as the aim of the entire study was to prevent women from becoming psychosocially maladjusted, we stress that it is not. We expected women who did not participate in the intervention programs to deteriorate at least a little, which did not happen. Finally, as stated before, the women in this study sample might have been less motivated at the start of the study than participants who are self-referred and are highly motivated to participate in a psychosocial intervention program. However, at the end, more than 90% of the women stated that the intervention was helpful to them; with over more than half of them saying that it had helped them a great deal.

References

1. Marchant DJ (1994). Invasive breast cancer. Surgical treatment alternatives. *Obstetrics and Gynaecology Clinics of North America*, 21: 659-679.
2. Robert NJ (1994). Adjuvant therapy in breast cancer. *Obstetrics and Gynaecology Clinics of North America*, 21: 693-707.
3. Eindhoven Cancer Registry (1995). *Cancer Incidence and Survival in the South East of the Netherlands 1955-1994*. Coeberg J.W.W., van der Heyden L.H. & Janssen-Heijen M.L.G. (Eds) Eindhoven, The Netherlands.
4. Irvine D, Brown B, Crooks D, Roberts J & Browne G (1991). Psychosocial adjustment in women with breast cancer. *Cancer*, 15: 1097-1117.
5. Kiebert GM, de Haes JCJM & van de Velde CJH (1991). The impact of breast conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*, 9: 1059-1070.
6. Helgeson VS & Cohen S (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15: 135-148.
7. Trijsburg RW, van Knippenberg FCE & Rijpma SE (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine*, 54: 489-517.
8. Meyer TJ & Mark MM (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, 14: 101-108.
9. Leszcz M & Goodwin PJ (1998). The rationale and foundations of group psychotherapy for women with metastatic breast cancer. *International Journal of Group Psychotherapy*, 48: 245-273.
10. Spiegel D, Morrow GR, Classen C, Raubertas R, Stott PB, Mudaliar N, Pierce HI, Flynn PJ, Heard L & Riggs G (1999). Group psychotherapy for recently diagnosed breast cancer patients: A multicenter feasibility study. *Psycho-Oncology*, 8: 482-493.
11. Classen C, Butler LD, Koopman C, Miller E, DiMiceli S, Giese-Davis J, Fobair P, Carlson RW, Kraemer HC & Spiegel D (2001). Supportive-Expressive group therapy and distress in patients with metastatic breast cancer. *Archives of General Psychiatry*, 58: 494-501.
12. Sheard T & Maguire P (1999). The effect of psychological interventions on anxiety and depression in cancer patients: Results of two meta-analyses. *British Journal of Cancer*, 80: 1770-1780.
13. Baider I, Peretz T, Hadani PE & Koch U (2001). Psychological intervention in cancer patients: A randomized study. *General Hospital and Psychiatry*, 23: 272-277.
14. Spiegel D, Bloom JR & Yalom I (1981). Group support for patients with metastatic cancer. A randomized prospective outcome study. *Archives of General Psychiatry*, 38: 527-533.
15. Telch CF & Telch MJ (1986). Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. *Journal of Consulting and Clinical Psychology*, 54: 802-808.
16. Fawzy FI, Cousins N, Fawzy NW, Kemeny ME, Elashoff R & Morton D (1990). A structured psychiatric intervention for cancer patients. *Archives of General Psychiatry*, 47: 720-725.
17. Cunningham AJ, Lockwood GA & Edmonds CV (1993). Which patients benefit most from a brief, group coping skills program? *International Journal of Psychiatry in Medicine*, 23: 383-398.
18. van der Pompe G (1997). *Mind-body Interactions in Breast Cancer. Neuroendocrine and Immune Aspects of Acute Psychological Stress and Psychosocial intervention in Breast Cancer Patients*, Dissertation, Erasmus University Rotterdam, The Netherlands.
19. Edelman S, Bell DR & Kidman AD (1999). A group cognitive behavior therapy programme with metastatic breast cancer patients. *Psycho-Oncology*, 8: 295-305.
20. Helgeson VS, Cohen S, Schulz R & Yasko J (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry*, 56: 340-347.
21. Bloom JR & Spiegel D (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. *Social Science and Medicine*, 19: 831-837.
22. Lichtman RR, Taylor SE & Wood JV (1987). Social support and marital adjustment to breast cancer. *Journal of Psychosocial Oncology*, 5: 47-74.

23. Noll Hoskins C, Baker S, Sherman D, Bohlander J, Bookbinder M, Budin W, Ekstrom D, Knauer C & Maislin G (1996). Social support and patterns of adjustment to breast cancer. *Scholarly Inquiry for Nursing Practice: An International Journal*, 10: 99-123.
24. Hitch PJ, Fielding RG & Llewelyn SP (1994). Effectiveness of self-help and support groups for cancer patients: A review. *Psychology and Health*, 9: 437-448.
25. Samarel N, Fawcett J & Tulman L (1997). Effect of support groups with coaching on adaptation to early stage breast cancer. *Research in Nursing & Health*, 20: 15-26.
26. Helgeson VS, Cohen S, Schulz R & Yasko J (2000). Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology*, 19: 107-114.
27. Bottemley A, Hunton S, Roberts G, Jones L & Bradley C (1996). A pilot study of cognitive behavioral therapy and social support group interventions with newly diagnosed cancer patients. *Journal of Psychosocial Oncology*, 14: 65-83.
28. Edmonds CVI, Lockwood GA & Cunningham AJ (1999). Psychological response to long term group therapy: A randomized trial with metastatic breast cancer patients. *Psycho-Oncology*, 8: 74-91.
29. Badger TA, Braden CJ, Longman AJ & Mishel MM (1999). Depression burden, self-help interventions, and social support in women receiving treatment for breast cancer. *Journal of Psychosocial Oncology*, 17: 17-35.
30. Schreurs PJG, van de Willige G, Brosschat JF, Tellegen B & Graus GMH (1993). *De Utrechtse Coping Lijst. Omgaan met Problemen en Gebeurtenissen. Herziene Handleiding*. Swets & Zeitlinger B.V., Lisse, The Netherlands.
31. de Bruin EJ & van Dijk M (1996). *Health and Disease Inventories. Een meetinstrument voor Aanpassingen aan Kanker. Handleiding*. Swets & Zeitlinger B.V., Lisse en Helen Dowling Instituut, Rotterdam, The Netherlands.
32. de Haes HCJM (1988). *Kwaliteit van leven van kankerpatiënten*. Dissertation, Rijksuniversiteit Leiden, Lisse Swets & Zeitlinger, The Netherlands.
33. de Groot MH (1991). Psychometrische aspecten van een stemmingsschaal (verkorte POMS). *Gedrag en Gezondheid*, 20: 46-51.
34. Sprangers MAG, Groenvold M, Arraras JI, Franklin J, te Velde A, Muller M, Franzini L, Williams A, de Haes HCJM, Hopwood P, Cull A & Aaronson NK (1996). The EORTC Breast Cancer-Specific Quality of Life Module (QLQ-BR32): First results from a three-country field study. *Journal of Clinical Oncology*, 14: 2756-2768.
35. Osoba D, Aaronson N, Zee B, Sprangers M & te Velde A (1997). Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. *Quality of Life Research*, 6: 103-108.
36. Bergner M, Bobbit RA, Carter WB & Gilson BS (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19: 787-805.
37. Yalom ID (1980). *Existential Psychotherapy*, New York, Basic Books.
38. Remie ME, Vos PJ, Maex E, Visser AP & Garssen B (1997). *Psychotherapeutisch Begeleiding van Vrouwen met Borstkanker*, Internal report, Helen Dowling Institute Rotterdam, The Netherlands
39. Vos PJ, Garssen B, Visser AP, Duivendoorn HJ & de Haes HCJM (2004). Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling. *Journal of Behavioral Medicine*, 27: 557-580.
40. Cohen J & Cohen P (1983). *Applied Multiple Regression/Correlation Analysis for the behavioral Sciences (2nd edition)*. Hillsdale, NJ Erlbaum.
41. Glantz SA & Slinker BK (1990). *Primer of applied regression and analysis of variance*. New York, McGraw-Hill.
42. Tarrier N & Maguire P (1984). Treatment of psychological distress following mastectomy: An initial report. *Behavioral Research and Therapy*, 22: 81-84.
43. Berglund G, Bolund C, Gustafsson UL & Sjodens PO (1994). A randomised study of a rehabilitation program for cancer patients: The 'starting again' group. *Psycho-Oncology*, 3: 109-120.
44. Cain EN, Kohorn EI, Quinlan DM, Latimer K, & Schwartz PE (1986). Psychosocial benefits of a cancer support group. *Cancer*, 57: 183-189.
45. Youssef FA (1984). Crisis intervention: A group-therapy approach for hospitalised breast cancer patients. *Journal of Advanced Nursing*, 9: 307-313.

46. Helgeson VS, Cohen S, Schulz R & Yasko J (2001). Group support interventions for people with cancer. In Baum A. & Andersen B.L. (Eds). *Psychosocial Interventions for Cancer*. American Psychological Association, Washington, DC, 269-286.
47. Edelman S, Craig A & Kidman AD (2000). Group interventions with cancer patients: Efficacy of psychoeducational versus supportive groups. *Journal of Psychosocial Oncology*, 18: 67-85.
48. Carver CS, Pozo, C, Harris SD, Noriega V, Scheier MF, Robinson DS, Ketcham AS, Moffat jr. FL & Clark KC (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65: 375-390.
49. Schover LR, Yetman RJ, Tuason, Meisler E, Esselstyn CB, Hermann RE, Grundfest-Broniatowski S & Dowden RV (1995). Partial mastectomy and breast reconstruction. A comparison of their effects on psychosocial adjustment, body image and sexuality. *Cancer*, 75: 54-64.
50. McCaul K, Sandgren AK, King B, O'Donnell S, Brandstetter A & Foreman G (1999). Coping and adjustment to breast cancer. *Psycho-Oncology*, 8: 230-236.
51. Schnoll RA, Harlow LL, Stolbach LL & Brandt U (1998). A structural model of the relationships among stage of disease, age, coping and psychological adjustment in women with breast cancer. *Psycho-Oncology*, 7: 69-77.
52. Edgar L, Rosberger Z & Nowlis D (1992). Coping with cancer during the first year after diagnosis. Assessment and intervention. *Cancer*, 69: 817-828.
53. Edgar L, Rosberger Z & Collet JP (2001). Lessons learned: Outcomes and methodology of a coping skills intervention trial comparing individual and group formats for patients with cancer. *International Journal of Psychiatry in Medicine*, 31; 289-304.

4

Effects of delayed psychosocial interventions versus early psychosocial interventions for women with early stage breast cancer

Petra J. Vos

Adriaan P. Visser

Bert Garssen

Hugo J. Duivenvoorden

Hanneke C.J.M. de Haes

Abstract

The importance of psychosocial counseling after a diagnosis of cancer has been acknowledged and many intervention studies have been carried out, with the aim to find out which types of intervention are most effective in enhancing quality of life in cancer patients. A factor which could be part of effective counseling could be the time of offering psychosocial counseling. In the present study 67 women with early stage breast cancer were randomised in a psychosocial group intervention program starting within four months after surgery or in the same intervention program starting at least three months later. The aim of this study was to research the effect of time of enrolment in a psychosocial group intervention on psychosocial adjustment. The main conclusion of this study is that women who started with their intervention early were less distressed at six months follow-up than women who were in the delayed condition. Medical and demographic variables were predictive for some psychosocial adjustment indicators, but were not associated with time of enrolment. Regardless of time of enrolment, women improved in distress, body image and recreational activities, but showed a decrease in social interaction. Though results are limited, based on these results we suggest that psychosocial counseling should be offered as soon after diagnosis or surgery for breast cancer as possible.

Introduction

Medical treatment of breast cancer has improved significantly in the past decades. Consequently, patients live longer and the character of the disease has changed [1-3]. Yet, being diagnosed with breast cancer is still experienced as life-threatening, often accompanied with psychosocial problems [4-7]. Acknowledging these problems, many psychosocial intervention programs have been developed and tested [8-11]. Its effectiveness in reducing emotional distress and improving coping abilities has been demonstrated in many studies [8-11].

The literature on interventions especially designed for women with breast cancer is extensive, with mixed results. Positive results were reported by Spiegel and co-workers [12]. Not only did the women who participated in the psychosocial support group live longer, they also reported a decline in psychological distress compared to women in the control group. Other intervention studies among women with breast cancer report only significant improvement of psychosocial adjustment just after the intervention is completed [13-15], which sometimes was not enhanced at follow-up a few months later [14]. In other long-term studies the improvement was only slightly at the end of the intervention, but significant at follow-up [16-18]. These studies do not only report changes over time, but also in comparison with a control group [12,15,18]. However, not all intervention studies show positive results. An intervention study by Edmonds and colleagues [19] yielded a slight positive change in distress, but this change was noted in both participants and non-participants. In a study of Winick and Robins [20] there were changes in distress, but these changes were mainly due to type of surgery and age, rather than to the interventions in which women participated. In another part of the recent study, we found that women who participated in an intervention program did not differ just after completion of the intervention from women who were on a three months waiting list and who were about to start with the intervention program [21].

A possible reason for these inconsistencies could be the differences in time in which the interventions have been offered. Some studies are limited to patients who are newly diagnosed [8,11,22,23] or to patients who recently had surgery [15], while in other studies time since diagnoses was not an in- or exclusion criterion [7,12,22,24]. It should also be noted, that time since diagnosis is not always mentioned [13]. Bloom and Kessler [25] suggested that early intervention could be important, because women are at risk for significant depression and mood disturbances in the first months after surgery. However, they also reported that women who did not receive any kind of counseling, were better adjusted 12-15 months after surgery than they were within three months after surgery. In a study by Edgar and co-workers [26] amongst patients with cancer of various sites, time of starting the intervention did not appear to be significant. Both participants of the early and of the late starting interventions reported significant improvement in psychosocial adjustment. There were no differences in therapy outcome for the early and delayed intervention.

The present study investigates the effects of a psychosocial group intervention for women with early stage breast cancer starting within four months after surgery or at least three months later. When the intervention starts within four months after surgery, we called it an early intervention. Most women in our study group, who were assigned to this condition, were still under medical treatment or had just finished it. The intervention consists of an experiential-existential group psychotherapy or participation in a social support group condition. These two forms were combined, because we could not demonstrate differences in intervention outcome as reported earlier [27]. The present part of the study focuses only on the effect of time of enrolment in an psychosocial group intervention on psychosocial adjustment. In addition, we describe whether demographic and medical variables are associated with psychosocial adjustment both at short-term and at long-term.

Methods

Subjects and procedures

Patients were recruited from several hospitals in the region of Rotterdam, The Netherlands. Eligible women were between 18 and 70 years of age, had surgery for primary breast cancer no longer than four months ago at the time of the first contact, had no distant metastases, sufficient knowledge of the Dutch language, and no psychiatric illness. They were informed about the study by an oncology nurse, who also judged the absence of psychiatric illness. Women were told that they would be randomly allocated to one of four conditions after the first interview: Early start or starting after a waiting period of several months, and experiential-existential group psychotherapy or social support group. If a woman was not motivated to participate, she could indicate this by returning an answering-form. If not returned within three weeks, the investigator attempted to contact the women by telephone. If they consented, an appointment was made for the first interview. During this interview women were asked to sign a written informed consent and a set of questionnaires was handed over. Women were asked to complete these questionnaires at their earliest convenience. After receiving the questionnaire, a patient was randomised into one of two conditions: Early start or late start of the intervention. The intervention programs lasted three months. There were three measurements for all participants: The first was before randomisation (T0), the second just after completion of the intervention (T1), and the final measurement six months after completion of the intervention (T2).

Variables and instruments

Medical and demographic data were obtained from a questionnaire containing anamnestic questions (size of tumor, date of diagnosis and surgery, type of surgery, number of affected lymph nodes, adjuvant therapy) and demographic questions (age, education, marital status,

work status). The oncology nurse, who referred patients to the researcher, checked the information in medical records.

Psychosocial adjustment was measured with the Dutch version of the Profile of Moods States (POMS), containing the subscales Depression, Anger, Fatigue, Tension, and Vigour [28], with the subscale Body Image and Sexual Functioning of the breast cancer specific module (QLQ-BR32) [29] of the EORTC QLQ-30 [30], and the subscales Recreation and Social Interactions of the Sickness Impact Profile (SIP) [31].

More information about the used questionnaires is described elsewhere [21,32].

All data, with the exception of the subscale Recreation of the SIP were collected at all measurements. The subscale Recreation of the SIP was only included at T0 and T1.

Interventions

In both types of interventions women met for 12 weeks for 2.5 hours. After the regular weekly sessions two follow-up sessions were scheduled, one and two months later. Both groups were closed groups in which six to ten women could participate. The groups were led by two trained group leaders, of which at least one had to be a woman.

The psychotherapy group was based on Experiential-Existential premises [33], enriched with Cognitive Behavioral components [34], which was adapted for women with breast cancer. A specific manual was developed for this group [35]. Therapists who were leading this group were familiar with this kind of therapy and were trained in how to lead a group in a study design.

The social support group had no specific manual. It was designed to let breast cancer patients share their mutual experiences with respect to the diagnosis and treatment for breast cancer. Group leaders were especially trained by the Comprehensive Cancer Centre Rotterdam to lead this kind of group. They could ask for intervision and feedback from the trainer during the study period.

The topics discussed in each of the interventions were not fixed beforehand per session, but were chosen by the group members themselves. They had to choose the topic from a list of topics (see Box 1). Both interventions were already used in standard care. They are described in more detail elsewhere [27].

Statistical analyses

Missing data on item level were imputed if no more than 25% of item scores for a particular subscale and a particular participant were missing and if a subscale consisted of at least four items. The mean score of the remaining item scores of the pertinent person on the subscale at issue was multiplied by the mean of the scores of the other participants on that particular item. This score was then divided by the overall mean of that subscale.

Because of the high ratio between dependent variables and the number of participants, we limited the number of variables in the analyses. Intercorrelation coefficients were determined

Box 1: Topics to be discussed in intervention

Topics which should be discussed in the psychosocial group interventions
<p>First session:</p> <ul style="list-style-type: none"> - Introduction - Rules of the group - Feeling safe in the group <p>All other sessions:</p> <ul style="list-style-type: none"> - Personal meaning of having (had) cancer - Fear of recurrence - Coping with feelings of uncertainty and control - Coping with emotions - Self image - Body image - Sexuality - Intimacy - Asking for social support - Giving social support - Coping with the partner - Coping with other relatives - Coping with the past - Saying goodbye/farewell - Holding on to changes - Going on without going to 'the group'

for subscales of the POMS. In case of sufficiently high intercorrelations, Principal Component Analyses were performed on the subscales of the POMS. This procedure has been described in more detail elsewhere [32].

Differences between the groups (early start vs. late start) with regard to demographic and medical variables and with regard to the baseline values of psychosocial adjustment were tested with univariate analyses of variance (ANOVA) for the continuous data and Chi-square analyses for ordinal data.

The intervention effect was analyzed with univariate analyses of covariance (ANCOVA). These analyses were performed on all outcome variables at T2, using the baseline values (T0 values) of the corresponding variable as covariates and time of enrolling in the intervention (early start or late start) as the independent variables.

In addition, we used a more subtle method, namely, Random Regression Modeling (RRM) to simultaneously estimate the effect of passage of time, time of enrolling in the intervention (i.e. early or delayed start of the intervention), type of intervention (experiential-existential group psychotherapy or social support group), age, type of surgery and stage of the disease on all outcome variables. RRM has many advantages above repeated measures ANCOVA and 'classical' regression analysis: It allows for missing data or an unequal number of data for each subject, and for the inclusion of fixed and time varying covariates. Furthermore, a realistic covariance structure (as opposed to compound symmetry or independence between repeated measures) can be implemented [36].

We ran two series of analyses with each six different, corresponding tests. The first series focused only on therapy effect and included time, time of enrolment and type of intervention as predictors. Of the six tests, time was incorporated as a fixed term (the slope of all individuals are equal) in three analyses and as a random term (slopes of individuals are specific per individual) in the other three. One analysis considered time as a linear variable, the second type included the time-square variable as a predictor and the third analysis added two interaction terms: time x time of enrolment and time x type of intervention. These interaction terms are most important for evaluating intervention effects, as one expects different changes over time in adjustment levels for the treatment modalities time of enrolment and type of intervention.

The second series of model testing were the same as the first (thus six models were tested for each outcome variable) with the incorporation of the variables 'age', 'stage of the disease' and 'type of surgery'.

The maximum likelihood method was used to test which model fitted best. A model was decided to have a better fit, if the maximum likelihood was at least significant better than the previous model [36]. All significant testing was fixed at 0.05 (two-tailed).

Results

Sample characteristics

Two hundred and fifty one eligible women were contacted by the investigators by telephone. Initially, one hundred and four women (41.4%) agreed to participate. These women were interviewed. Finally 87 (34.7%) women enrolled into the study. The reasons for not participating of 164 women were: 1) not interested (N = 26), 2) having enough support (N = 26), 3) being too emotionally distressed (N = 14), 4) could not be reached by telephone (N = 19), 5) other reasons such as distance and time (N = 27), and 6) unknown (N = 52). It is not known whether non-participants differ from participants, since no data were available from women who refused to participate.

Of the 87 women who started the study, sixty seven women (77.0%) completed the study. Of the 20 women who dropped out, one woman died, for two women attending a group became too emotional, three women were too ill to attend group meetings, for one woman the group meetings were not what she had expected, and thirteen women did not feel like participating anymore without giving further reasons. Women who stopped participating, were significantly older (53.2 years, SD = 7.21) than women who continued participation (49.0 years, SD = 7.92). They did not differ on other demographic, medical and baseline outcome variable.

Of the 67 participants who completed the study, twenty women had affected lymph nodes. Most participating women had a mastectomy (65.7%). Three of them had had a breast re-

Table 1: Medical and demographic characteristics

	Early start N = 33	Delayed start N = 34	Total patients N = 67	%
Time between surgery and T0 (weeks)				
Mean	11.6	12.2	11.9	
Stage				
0	2	1	3	4.5
I	12	12	24	35.8
II	13	18	31	46.2
III	2	1	3	4.5
Missing	4	2	6	9.0
Number of affected lymph nodes				
0	25	22	47	70.1
1-4	7	7	14	20.9
>4	1	4	5	7.5
Missing	0	1	1	1.5
Type of surgery				
Breast conserving therapy	11	12	23	34.3
Mastectomy	22	22	44	65.7
Age (years)				
Mean	49.9	48.1	49.0	
Highest education				
Primary school	3	2	5	7.5
Secondary school	21	24	45	67.1
Higher education	7	7	14	20.9
Missing	2	1	3	4.5
Marital status				
Partner	27	23	50	74.6
Single	5	10	15	22.4
Missing	1	1	2	3.0

construction at T0. The mean age was 49.0 years (range 29-68, SD 7.92). Most women had finished secondary school as their highest education (67.1%). Fifty women had a partner, six of whom were not living with their partner. Of the 16 women who were single, three were never married, ten were divorced and two women were widowed. Medical and demographic data are summarized in Table 1.

Of the 67 women participating, 33 were assigned to the early start of the intervention program, while the other 34 were assigned to the delayed start condition. Of the 33 women who were assigned to the early starting intervention condition, 19 participated in the group psychotherapy condition and 14 in the social support group condition. Of the women who were assigned to the delayed interventions, 16 participated in the psychotherapy group intervention and 18 in the social support group. The mean time since surgery for women who started in the early intervention was 19.6 weeks (SD = 9.03) and for the women of the delayed intervention it was 31.9 weeks (SD = 7.41).

Women who started their intervention early did not differ on any demographic, medical or baseline variable from their counterparts who participated in the delayed intervention condition.

Data reduction

Intercorrelation-coefficients were determined for the subscales of the POMS. Intercorrelations of the POMS-subscales ($r \geq 0.35$) were all statistically significant. Therefore, a Principal Component Analysis with Varimax Rotation was performed on the subscales of the POMS, which resulted in a two-dimensional solution. The first dimension represents Distress and comprised the subscales Depression, Anger and Tension. The second dimension is composed of the subscales (reverse of) Fatigue and Vigour and represents Vitality. For both components, the means were calculated and used in the following analyses.

Impact of time of enrolment

The ANCOVA's showed that time of enrolment in the intervention is significant associated with distress at T2. Those who enrolled later in the intervention, appeared to be more distressed at follow-up than women who start with the intervention earlier ($p = 0.03$), controlling for baseline differences (See Figure 1). After completion of the intervention (T1), this difference was not significant.

Changes over time

As indicated we have tested two series of models: One with therapy predictors and another series that incorporated also medical and demographic variables. The fit of the more comprehensive models was always significant better ($p \leq 0.05$) than for models without medical and demographic variables. Models in which time was assumed to be fixed were best fitting for

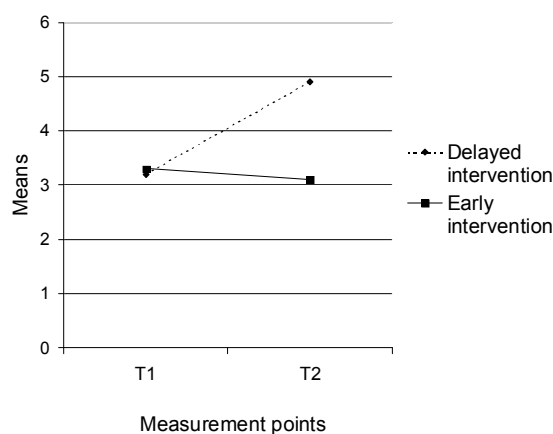


Figure 1: Changes in distress with early and delayed intervention

Table 2: Estimation of adjustment variables by explanatory variables

Adjustment variable	Distress t	Vitality t	Body Image t	Sexual Functioning t	Social Interactions t	Recreation t
Explanatory variables						
Time	-1.59	0.01	2.75*	-1.10	-1.86	-2.74*
Time of enrolling in the intervention	0.95	-0.69	-0.30	1.12	-0.05	0.17
Type of intervention	-0.61	0.96	0.00	-0.78	-1.01	-0.24
Age	-1.12	0.83	2.25*	1.27	-1.16	-0.58
Type of surgery	1.20	-0.56	-3.80*	1.69	0.73	0.48
Stage of disease	0.22	-0.57	1.15	-1.71	1.26	1.60

* = Significant at $p \leq 0.05$

some outcome variables (Body Image, Sexual functioning and Recreation), whereas for other variables incorporating time as a random factor yielded the best fitting model. Models that included interaction terms were not significantly better than models without these terms.

As can be learned from Table 2, there were changes over time in Distress, Body Image, Social Interactions and Recreation. The changes in Body Image and Recreation were significant. Body image improved and number of recreational activities increased. The changes in Distress and Social Interactions were non-significant. Distress and the number of social interactions decreased over time. None of the therapy modalities (time of enrolment and type of intervention) had any effect on outcome variables. Of the three additional predictors, age and type of surgery had an effect on psychosocial adjustment. Older women and women with breast conserving therapy reported a more positive body image than younger women and women who had a mastectomy. In the same line, breast conserving therapy was also associated with better sexual functioning. Women with a more positive stage of disease reported better sexual functioning compared to women with a more unfavourable stage, although this effect was not significant.

Discussion and conclusion

Discussion

We tested whether women who were diagnosed with a primary breast cancer, benefited more from a psychosocial group intervention program when it was offered within four months after surgery compared to participation at least three months later.

We found that women offered the intervention at a later point in time were significantly more distressed six months after completion of the intervention compared to women who started within four months after surgery. This result suggests that women with early stage breast cancer should be able to get psychosocial counseling early after surgery, rather than waiting until a later moment.

Age, stage of the disease and type of surgery were associated with some of the psychosocial adjustment variables, but not with the time of offering the intervention. Our results are in line with results reported by Dunn and colleagues [37], who noted that women who were visited by a volunteer who had had breast cancer benefited more from this supportive visit when they were still in hospital than when the visit took place at a later point in time. Our result seems to contradict the findings of Bloom and Kessler [25] who found that after 12-15 months after surgery women were better adjusted than just after surgery. In the present study follow-up was only 6 months and no changes could be reported. It could be that at twelve months follow-up, women are changed in a positive way. Bloom and Kessler advised to offer psychosocial intervention at a more distant time from surgery (i.e. after 9 months). However, based on the presented results, we cannot confirm the results of Bloom and Kessler. Finally, Edgar and co-workers [26] found no differences between different times of starting psychological interventions. They reported that, regardless of intervention timing, all women with breast cancer experienced lower levels of distress at 12 months follow-up. In line with the present study, they found no relationship between distress level and the patients' stage of illness.

Knowing that time of enrolment in the intervention was of no significance for the outcome at 6 months follow-up for most psychological adjustment variables, we also studied whether patients' psychological adjustment had changed over time. In our study sample a weak relationship between Distress and Time and Social Interactions and Time exist. At follow-up women are less distressed and report less social interactions. The change over time in Body Image and Recreation was significant: Both psychosocial adjustment indicators improved at follow-up. Results of other studies on therapy effect are sometimes similar [18,19,38], whereas in a study of Antoni and co-workers [16] participants reported less depressive symptoms, but not an improvement in distress. A decline in depressive symptoms was also found by Youssef [13], but in his study sample participants fell within the range of depressed out-patients, while our study sample consisted of women who were well adjusted psychosocially at the start of the study. Other studies also report significant positive changes, though these changes were sometimes found in both the intervention and the control group [15,39] or were only short-term [14,40]. In the study of Heinrich and colleagues [39] the observed changes were only for psychological adjustment and not for level of activity, while our results suggests an improvement in recreational activities.

A second aim of the present study was to find out whether demographic and medical variables were associated with psychosocial adjustment at follow-up. Age appeared to be associated with Body Image: Older women reported a more positive body image than younger women do. As expected, women who underwent a mastectomy reported a low body image at follow-up and had more problems with sexual functioning. This was also found in other studies among women with breast cancer [6,41].

A limitation of the present study could be that finally 26.7% of all eligible women completed the study. Although this is not a very high participation percentage, it confirms what is reported in other randomised intervention studies, which fully describe the number of eligible patients and the number of patients who completed the study [19,26,42]. Randomised studies with higher participation rates usually do not describe how many eligible patients were invited to participate or how many eligible patients were reached by other means [12,15,18,43]. These studies give, in our opinion an underscore of the real number of eligible patients. We stress that the women of our study are representative for women who are diagnosed with breast cancer and are willing to participate in a psychological intervention program.

Another limitation of the present study could be the short time between the start of the two interventions (three months). Bloom and Kessler [25] suggested at the end of their study that it would be preferable that cancer patients would start in an intervention program at least nine months after surgery and not as soon as possible. However, results of other studies [44,45] suggest that patients who do not participate in a psychosocial intervention, show a decline in psychological adjustment [44,45]. Telch and Telch [44] did even attributing the found therapy effect mainly to this decline. To study whether Bloom and Kessler [25] were right with their conclusion, or whether patients should be offered psychosocial counseling as soon after surgery as possible, the ideal situation would be one in which one group of women would start with their intervention within three months after surgery and one group starting the intervention about nine to twelve months after surgery, because many patients have the strength themselves to adjust psychosocially rather well. However, the delay in the present study was set to a maximum of seven months because of ethical reasons. During the time in which the women could not participate in the intervention groups, they were not offered any kind of counseling, apart from the standard support they would receive from their hospital. Neither did they receive any kind of information or education about breast cancer from the researchers in the mean time. It was viewed unethical to withdraw women too long from psychosocial counseling.

Conclusion

We may conclude from this study, that the time of offering a psychosocial intervention program, no matter whether it is a group psychotherapy intervention or a social support group, to women suffering from breast cancer, is not related with changes in psychosocial adjustment. Passage of time was only related with Recreation and Body Image, and seems only to be weakly related with Distress and Social Interactions. However, those women who started in the delayed psychosocial intervention program, were more distressed at follow-up than women who started within four months after surgery.

Practice Implication

Based on these results, we suggest that women should be able to start with a psychosocial intervention program as soon as possible after surgery, to prevent them from becoming distressed. However, since in this study the delay in starting in an intervention was short (only three months), and our study sample was not that large, we recommend to test this suggestion in a larger study sample and with a longer delaying period.

References

1. Marchant DJ (1994). Invasive breast cancer. Surgical treatment alternatives. *Obstetrics and Gynaecology Clinics of North America*, 21: 659-79.
2. Robert NJ (1994). Adjuvant therapy in breast cancer. *Obstetrics and Gynaecology Clinics of North America*, 21: 693-707.
3. Eindhoven Cancer Registry (1995). *Cancer Incidence and Survival in the South East of the Netherlands 1955-1994*. Coeberg J.W.W., van der Heyden L.H. & Janssen-Heijen M.L.G. (Eds) Eindhoven, The Netherlands.
4. Irvine D, Brown B, Crooks D, Roberts J & Browne G (1991). Psychosocial adjustment in women with breast cancer. *Cancer*, 15: 1097-117.
5. Fallowfield L (1991). Counselling patients with cancer. In Davis H. & Fallowfield L. (Eds.) *Counseling and Communication in Health Care*. John Wiley & Sons Ltd, 253-269.
6. Kiebert GM, de Haes JCJM & van de Velde CJH (1991). The impact of breast conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*, 9: 1059-1070.
7. Helgeson VS & Cohen S (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15: 135-148.
8. Andersen BL (1992). Psychological interventions for cancer patients to enhance quality of life. *Journal of Consulting and Clinical Psychology*, 66: 552-556.
9. Trijsburg RW, van Knippenberg & FCE, Rijpma SE (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine*, 54: 489-517.
10. Meyer TJ & Mark MM (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, 14: 101-108.
11. Leszcz M & Goodwin PJ (1998). The rationale and foundations of group psychotherapy for women with metastatic breast cancer. *International Journal of Group Psychotherapy*, 48: 245-273.
12. Spiegel D, Bloom JR & Yalom I (1981). Group support for patients with metastatic cancer. A randomised prospective outcome study. *Archives of General Psychiatry*, 38: 527-533.
13. Youssef FA (1984). Crisis intervention: A group-therapy approach for hospitalized breast cancer patients. *Journal of Advanced Cancer Nursing*, 9: 307-313.
14. Edelman S, Bell DR & Kidman AD (1999). A group cognitive behaviour therapy programme with metastatic breast cancer patients. *Psycho-Oncology*, 8: 295-305.
15. Samarel N, Fawcett J & Tulman L (1997). Effect of support groups with coaching on adaptation to early stage breast cancer. *Research in Nursing Health*, 20: 15-26.
16. Anotoni MH, Lehman JM, Kilbourn KM, Boyers AE, Culver JL, Alferi SM, Yount SE, McGregor BA, Arena PL, Harris SD, Price AA & Carver CS (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early stage breast cancer. *Health Psychology*, 20: 20-32.
17. Spiegel D, Morrow GR, Classen C, Raubertas R, Stott PB, Mudaliar N, Pierce HI, Flynn PJ, Heard L & Riggs G (1999). Group psychotherapy for recently diagnosed breast cancer patients: A multicenter feasibility study. *Psycho-Oncology*, 8: 482-493.
18. Classen C, Butler LD, Koopman C, Miller E, DiMiceli S, Giese-Davis J, Fobair P, Carlson RW, Kraemer HC & Spiegel D (2001). Supportive-Expressive group therapy and distress in patients with metastatic breast cancer. A randomised clinical intervention trial. *Archives of General Psychiatry*, 58: 494-501.
19. Edmonds CVI, Lockwood GA & Cunningham AJ (1999). Psychological response to long term group therapy: A randomized trial with metastatic breast cancer patients. *Psycho-Oncology*, 8: 74-91.
20. Winick L & Robbins GF (1977). Physical and psychologic readjustment after mastectomy. *Cancer*, 39: 478-486.
21. Vos PJ, Garssen B, Visser A, Duivenvoorden HJ & de Haes JCJM (2004). Psychosocial intervention for women with primary non-metastatic breast cancer: A comparison between participants and a non-intervention group. *Psychotherapy and Psychosomatics*, 73: 276-285.
22. Gellert GA, Maxwell RM & Siegel BS (1993). Survival of breast cancer patients receiving adjunctive psychosocial support therapy: A 10-year follow-up study. *Journal of Clinical Oncology*, 11: 66-69.

23. Hanson Frost M, Suman VJ, Rummans TA, Dose AM, Taylor M, Novotny P, Johnson R & Evans RE (2000). Physical, psychological and social well-being of women with breast cancer: The influence of disease phase. *Psycho-Oncology*, 9: 221-231.
24. Cope DG (1995). Functions of breast cancer support group as perceived by the participants: An ethnographic study. *Cancer Nursing*, 18: 472-478.
25. Bloom JR & Kessler L (1995). Risk and timing of counseling and support interventions for younger women with breast cancer. *Journal of the National Cancer Institute Monographs*, 16: 199-206.
26. Edgar L, Rosberger Z & Nowlis D (1992). Coping with cancer during the first year after diagnosis. Assessment and intervention. *Cancer*, 69: 817-828.
27. Vos PJ, Visser A, Garssen B, Duivenvoorden HJ & de Haes JCJM (2007). Effectiveness of group psychotherapy compared to social support groups in non-metastatic breast cancer. *Journal of Psychosocial Oncology*, 25: 37-60.
28. de Groot MH (1991). Psychometrische aspecten van een stemmingsschaal (verkorte POMS). *Gedrag en Gezondheid*, 20: 46-51.
29. Sprangers MAG, Groenvold M, Arraras JL, Franklin J, te Velde A, Muller M, Franzini L, Williams A, de Haes HCJM, Hopwood P, Cull A & Aaronson NK (1996). The EORTC Breast Cancer-Specific Quality of Life Module (QLQ-BR32): First results from a three-country field study. *Journal of Clinical Oncology*, 14: 2756-2768.
30. Osoba D, Aaronson N, Zee B, Sprangers M & te Velde A (1997). Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. *Quality of Life Research*, 6: 103-108.
31. Bergner M, Bobbit RA, Carter WB & Gilson BS (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19: 787-805.
32. Vos PJ, Garssen B, Visser AP, Duivenvoorden HJ & de Haes JCJM (2004). Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling. *Journal of Behavioral Medicine*, 27: 557-580.
33. Yalom ID (1980). *Existential Psychotherapy*. New York, Basic Books.
34. van der Pompe (1997). *Mind-body interactions in breast cancer. Neuroendocrine and immune aspects of acute psychological stress and psychosocial intervention in breast cancer*. Dissertation, Leiden, the Netherlands.
35. Remie ME, Vos PJ, Maex E, Visser AP & Garssen B (1997). *Psychotherapeutische Begeleiding van Vrouwen met Borstkanker*, Internal report, Helen Dowling Institute, Rotterdam, The Netherlands.
36. Gibbons RD, Hedeker D, Elkin I, Waternaux C, Kraemer HC, Greenhouse JB, Shae MT, Imber SD, Sotsky SM & Watkins JT (1993). Some conceptual and statistical issues in the analysis of longitudinal psychiatric data. Application to the NIHM treatment of Depression Collaborative Research Program dataset. *Archives of General Psychiatry*, 50: 739-750.
37. Dunn J, Steginga SK, Occhipinti S & Wilson K (1999). Evaluation of a peer support program for women with breast cancer – lessons for practitioners. *Journal of Community and Applied Social Psychology*, 9: 13-22.
38. Berglund G, Bolund C, Gustafsson U & Sjöden P (1994). A randomised study of a rehabilitation program for cancer patients: the 'starting again' group. *Psycho-Oncology*, 3: 190-201.
39. Heinrich RL & Coscarelli Schag C (1985). Stress and activity management: Group treatment for cancer patients and spouses. *Journal of Consulting Clinical Psychology*, 53: 439-446.
40. Cunningham AJ & Toco EK (1989). A randomised trial of group psychoeducational therapy for cancer patients. *Patient Education and Counseling*, 14: 101-114.
41. Moyer A (1997). Psychosocial outcomes of breast conserving surgery versus mastectomy: A meta-analytic review. *Health Psychology*, 16: 284-298.
42. Edgar L, Rosberger Z & Collet JP (2001). Lessons learned: Outcomes and methodology of a coping skills intervention trial comparing individual and group formats for patients with cancer. *International Journal of Psychiatry in Medicine*, 31: 289-304.
43. Cunningham AJ, Lockwood GA & Edmonds CV (1993). Which patients benefit most from a brief, group coping skills program? *International Journal of Psychiatry in Medicine*, 23: 383-398.
44. Telch CF & Telch MJ (1986). Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. *Journal of Consulting and Clinical Psychology*, 54: 802-808.

45. Bottomley A, Hunton S, Roberts G, Jones L & Bradley C (1996). A pilot study of cognitive behavioural therapy and social support group interventions with newly diagnosed cancer patients. *Journal of Psychosocial Oncology*, 14: 65-83.

5

Effectiveness of group psychotherapy compared to social support groups in patients with primary, non-metastatic breast cancer

Petra J. Vos

Adriaan P. Visser

Bert Garssen

Hugo J. Duivenvoorden

Hanneke C.J.M. de Haes

Abstract

The aim of the present study is to compare the effectiveness of experiential-existential group psychotherapy and a social support group for women with a primary breast cancer on psychosocial adjustment. Sixty-seven well adjusted women who had been operated for breast cancer no longer than four months prior to the start of the study were randomised into one of two conditions: Participating in the group psychotherapy or in the support group. They were questioned at the start of the study, at the end of the intervention and one year after completion of the intervention. Results at follow-up were mixed: Positive changes were reported for Body Image and Recreation, regardless of type of intervention. Other psychosocial adjustment indicators did not change.

In general, we may conclude that well-adjusted women diagnosed with breast cancer do not specifically benefit from these types of interventions.

Introduction

In the past decades the psychosocial problems patients encounter after being diagnosed with cancer have been extensively studied [1-4]. Acknowledging these problems, many intervention studies have been developed and tested. A review of the literature shows that most of these intervention programs are effective in reducing emotional distress and improving coping abilities [5-10]. Focussing on group interventions, Trijsburg and colleagues (1992) reported that group interventions were often as effective as the individual intervention programs they were compared with [6]. Edelman and colleagues (2000) reported positive results for psychoeducational interventions, but limited evidence for efficacy in reducing stress or improving psychosocial adjustment when supportive group interventions were reviewed [11]. Conclusions of Rehse and Pukrop (2003) were that especially interventions lasting more than 12 weeks were effective [12]. After reviewing the literature, Fawzy and Fawzy (1998) recommend a group intervention consisting of health education, stress management, behavioral training, coping skill training and psychosocial group support for patients who are newly diagnosed or in the early stage of their treatment [13].

The efficacy of interventions especially designed for women with breast cancer have been investigated in many studies as well. Again, most studies showed beneficial effects, but findings were not always consistent. A short psychotherapy group intervention for women with metastatic breast cancer yielded positive results just after completion of the intervention: Participants showed significant improvement in depression and total mood disturbances compared to non-participants. At follow-up, these differences were no longer apparent [14]. Another study among women with metastatic breast cancer who participated in a longer lasting psychotherapy group, showed no differences between participating women and women of the control group when mood or quality of life was concerned. However, the therapist reported profound clinical changes in the participating women [15]. Classen and colleagues (2001) found no differences between participants of a supportive-expressive therapy group in mood disturbance at first glance. When, however, the final assessment, which occurred within one year of death was removed from the analysis, participants of the intervention showed a greater decline in mood disturbance than controls did [16].

Intervention programs among women with early stage breast cancer show the same results as studies among women with metastatic breast cancer. Participants of a short psychotherapy intervention program reported positive results: Though psychosocial adjustment did not improve significantly just after the completion of the intervention, it did at six and twelve months follow-up, although the authors cannot rule out the possibility that the emotional course of these women would have been the same without the intervention [17]. Antoni and colleagues (2001) showed an improvement of early stage breast cancer patients who participated in a cognitive-behavioral stress management program. Not only after completion of the intervention was their distress declined, but this change was enhanced at 3 and

9-months follow-up [18]. In a study among depressed women with breast cancer, both the experimental and the control group improved, though the improvement was somewhat less for patients of the control group [19], while in a study of Samarel and co-workers (1997) no significant differences were found between participants of a social support group and women in a control group, though in both groups symptoms decreased over time [20]. The authors state that this lack of intervention effect could possibly be contributed to the early start of the intervention (2 months after surgery) and to the fact that all participating women were free of advanced disease and sufficient recovered from surgery. They were also not experiencing severe side effects from adjuvant therapy.

The abovementioned studies investigated both psychotherapy groups and social support groups. In our opinion, there are some objective differences between these types of interventions. First of all are psychotherapy groups usually led by psychotherapists and social support groups by leaders with different educational backgrounds. Psychotherapy groups often focus much more on the personal meaning of having (had) cancer and the accompanying experiences, while the focus of the social support groups is much more on practical aspects of having (had) cancer. A third difference is that psychotherapy is often less structured compared to social support groups. Although we have made a theoretical distinction between group psychotherapy and social support groups for this study, this distinction is not always sharp. Some interventions are called 'psychotherapy' while their content is mainly psycho-educative, supportive or based on coping skill training. Other interventions are called 'Social support groups' while in fact they offer much more than only providing social support.

A special type of interventions are interventions which are based on the principles of experiential therapy. The aim of this kind of therapy is to change the patients' experience of life and facilitate existential reorganisation. The approach is dynamic and its focus is on fundamental concerns of the patients' life such as fear of death, experience limitations of freedom, existential isolation, relationships, autonomy versus dependence and helplessness, and meaning of life [21-23]. In a famous study of Spiegel and co-workers (1981), women who participated in a psychological support group based on these principles not only lived longer than women in the control group, but also reported less tension, depression, fatigue and confusion and more vigor [24]. Results of a study of Goodwin and co-workers (2001) who replicated Spiegel's study, were comparable for psychological outcome [25]. However, a study done by Van der Pompe (1997) did not find a change in psychosocial adjustment [22]. All these mentioned studies were carried out among women with metastatic breast cancer. Cunningham and Edmonds (1996), concluded in their review, that there were not enough studies which researched interventions of this type to draw firm conclusions about the efficacy of these kind of group interventions [8].

The abovementioned studies investigated the effectiveness of a group intervention compared to a control group. Other studies examined the effects of one intervention compared with an intervention of another kind. Hosaka (1996) for instance, studied a group interven-

tion which was compared to an individually intervention program [26]. Findings showed that participants of both interventions improved in emotional distress, but they did not significantly differ from each other. Helgeson and co-workers (1999) studied two kinds of group interventions: Education groups and peer discussion groups, which were compared with a control group [27]. Findings of this study showed that at completion of the intervention there were no significant effects on positive affect, but a positive effect in the education group on vitality, while this effect was negative in the peer discussion group. At six months follow-up, the education groups showed a significant effect on positive affect, while in the peer discussion groups decremented effects were found for negative affect and vitality.

The aim of the present study is to compose the effectiveness of two types of interventions: 1) a group psychotherapy intervention, based on Experiential-Existential (EE) premises [21], and 2) a social support group intervention. Our first hypothesis is that participants of both interventions will improve on psychological, psychosexual and social adjustment. Secondly we expect that the participants of the EE group psychotherapy will improve significantly more than those of the social support groups, because in the therapy groups the focus will be on incorporating cancer in one's life instead of only exploring practical solutions to deal with the cancer at the very moment, as was done in the social support groups.

We expect also that Age, Type of surgery and Stage of the disease are predictive for all the psychosocial adjustment indicators one year after completion of the intervention programs.

Methods

Subjects and procedures

Patients were recruited from several hospitals in the region of Rotterdam, The Netherlands. The ethical committees of all participating hospitals approved of the study. Eligible participants were women between 18 and 70 years of age, who had surgery for primary breast cancer no longer than four months ago at the time of the first contact, no distant metastases, sufficient knowledge of the Dutch language, and no psychiatric illness. An oncology nurse, who also judged the absence of psychiatric illness, informed the women about the study during regular appointments. Women were told that they would be randomly allocated to one of two conditions after the first interview: Participating in an EE group psychotherapy or a social support group. The oncology nurse would hand a leaflet to the patients, so they could read the information about the study at home. If a woman was not motivated to participate, she could indicate this by returning an answering-form, which was enclosed into the leaflet. If not returned within three weeks, the investigator attempted to contact the women by telephone. If consent was given, an appointment was made for the first interview. During the interview women were asked to sign a written informed consent and a set of questionnaires was handed over at the end of the interview. Women were asked to complete these

questionnaires at their earliest convenience, but at least within one week and mail them to the researcher. After having received the questionnaires, patients were randomised into the group psychotherapy or the social support group. The intervention programs for both conditions lasted three months. There were three measurements: The first (T0) within four months after surgery, before randomisation and thus before the start of the intervention, the second just after completion of the intervention (T1) and the final measurement twelve months after completion of the intervention (T2).

Measures

Medical and demographic data were obtained from a general questionnaire containing anamnestic questions (size of tumor, date of diagnosis and surgery, type of surgery, number of affected lymph nodes, adjuvant therapy) and demographic questions (age, education, marital status, work status). The oncology nurse, who referred patients to the researcher, checked the information in medical records for those women who agreed to participate.

Three scales covered psychosocial adjustment. Emotional adjustment was measured with the Dutch version of the Profile of Mood States (POMS) [28], which measures mood states in five dimensions: Depression (8 items; $\alpha = 0.89$), Anger (7 items; $\alpha = 0.91$), Fatigue (6 items; $\alpha = 0.91$), Tension (6 items; $\alpha = 0.89$), and Vigor (5 items; $\alpha = 0.80$). A higher score indicates that a particular mood is experienced more often. The POMS should be scored on a 5-point scale.

Psychosexual functioning was measured with the subscales Sexual Functioning (2 items; $\alpha = 0.81$) and Body Image (4 items; $\alpha = 0.89$) of the breast cancer specific module (QLQ-BR32) [29] of the EORTC QLQ-30 [30]. The breast cancer specific module includes questions about side effects of different treatment modalities, body image and sexuality and should be scored on a 4-point scale. Higher scores on the subscale Body Image represent worse level of functioning, while higher scores in the subscale Sexual Functioning represent a better level of functioning.

Social adjustment was measured with the subscales Social Interactions (20 items; $\alpha = 0.75$) and Recreation (8 items; $\alpha = 0.75$) of the Sickness Impact Profile (SIP) [31]. This is a daily functioning questionnaire, which describes the impact of illness on behavior in 12 aspects. In this study, only two of these aspects were used, since the other aspects were already covered by other questionnaires, or were irrelevant for this study. In the questionnaire, statements should be answered with 'right' or 'not right'. Higher scores represent more impact of the illness.

Reliability and validity for a Dutch population were adequate for all used questionnaires [28,29,31].

Interventions

Both intervention types consisted of twelve weekly sessions of 2,5 hours, which included a 15 minute coffee-break. After the regular weekly sessions, two follow-up sessions were

scheduled, one and two months later. Both groups were closed groups, in which six to ten women could participate. Two trained therapists led the EE psychotherapy groups and two trained group leaders led the social support groups. At least one of the therapists or group leaders had to be a woman.

Group psychotherapy

Theoretical background The group psychotherapy is based on experiential therapy [32,33]. This means that in the therapy much attention is paid on themes such as awareness and joy in life, freedom and limitations, and meaning of life, and also on the way attention is paid to these themes. It is important to start from the here-and-now situation instead of changing 'wrong' behavior. Important elements of the existential approach were incorporated [32,33]. The emphasis lies on stimulation of exploration of needs, problems and personal strength to find personal solutions of problems.

Structure of the intervention In the first session the central theme is getting to know each other. Participants introduce themselves and give some background information about their illness, their motivation for participation and expectancies of what they will learn from their participation. All other sessions have the same structure: Start with a relaxation or mediation exercise, followed by a round in which each participant is invited to tell something about feelings of having cancer. From this round, the therapists summarize which topic is important at that moment for the group.

Information about important topics comes from the report by the therapists of what happened in the previous session and what the previous session had done to participants. The therapists use individual processes in the group setting in such a manner that these are helpful for all group members. The round functions as a basis for the rest of the session, in which the emphasis lies on addressing feelings and thoughts. In this part, the experiences of one or more group members are addressed. Half way through the session there is a 15-minute coffee break, in which the therapists leave the group. At the end of the session, the group members are shown possibilities and applications in daily life of what they have learned in the session. The session ends with a short relaxation or meditation exercise.

Topics of the session Because the focus of the intervention is on the needs of the participants, there is no fixed scheme of topics per session. However, some topics tend to come up in interventions for women with breast cancer and these topics are bound to be discussed in the course of the intervention (see Box 1). During one session, more than one topic can be discussed, and some topics can be discussed in more than one session and in more than one way. (see Box 2). The therapists use therefore a checklist, to make sure that each topic is discussed. In case a topic is not discussed, the therapist is bound to search for the cause of it, and will try to bring it in one of the sessions left.

Box 1: Topics to be discussed in both interventions

First session	Introduction:	<ul style="list-style-type: none"> – Introduction of group members – Rules of the group – Feeling safe in the group 		
All other sessions	(coping with) emotions:	<ul style="list-style-type: none"> – Fear of recurrence – Coping with emotions 		
	Coping with uncertainty:	<ul style="list-style-type: none"> – Coping with feelings of certainty and control 		
	Self-image:	<ul style="list-style-type: none"> – Blaming one self for cancer – Feelings of (lack of) personal control 		
	Body image, sexuality, intimacy:		<ul style="list-style-type: none"> – Feelings about sexuality – Feelings about 'ill' body – Changes of the body – Dealing with sexual relationships – Daring to be intimate (again) 	
		Learning from the past:	<ul style="list-style-type: none"> – Coping with the past 	
		Personal meaning of having cancer:	<ul style="list-style-type: none"> – Changes in faith after having cancer – Changing in dealing with life 	
		Support system:		<ul style="list-style-type: none"> – Asking for social support – Giving social support – Coping with the partner – Coping with other relatives
	Saying goodbye:			<ul style="list-style-type: none"> – Changes of lifestyle – New beginning – Saying farewell (to other groupmembers)
			Planning for the future:	<ul style="list-style-type: none"> – Holding on to changes – Going on without going to 'the group'

The themes of the follow-up sessions are fixed. In the first follow-up session, the central theme is holding on to the change one has made during the therapy. The theme of the second follow-up session is 'going on without the group'.

The procedures of the psychotherapy group are described in more detail elsewhere [34,35].

Social Support Group

The social support groups were designed to let breast cancer patients share their mutual experiences with respect to the diagnosis and treatment for breast cancer, and to receive information from experts on topics they are interested in. Usually these groups meet for 90 minutes, without a coffee break. However, for the sake of comparability, the duration of this group was extended to 2,5 hours with a coffee break. In making both the interventions 2,5 hours, we could guarantee that any result could not be subjected to the different length of interaction in the different kind of groups. Patients were encouraged to use the group to obtain peer support and emotional encouragement from other participants. It was based on the regular support groups provided by the Comprehensive Cancer Centre in Rotterdam. For this support group, no manual was developed. The social support groups were semi-structured: The structure of the sessions was fixed, but the participants had to give each session a specific theme by deciding which topic was discussed in the session. During the

Box 2: Ways of discussion topics in the EE group psychotherapy

Introduction	Exploration of the aim of the intervention; introducing group members; creation of safe surroundings; explanation of rules; inventarisation of expectancies
Emotions/coping with emotions	Exploration of members' own anxieties and anger; confrontation with anxieties of others; coping with anxiety
Coping with uncertainty	Making members aware of their own uncertainties
Self-image	Exploration of the theme "who am I"; paying attention to the influence of cancer and the following surgery on one's self-image; stimulation of acceptance; the feeling of 'I have a right to be here and to be who I am'
Body image, sexuality, intimacy	Experiences and changes in body image, sexuality and intimacy are discussed and participants learn from each other how to deal with these changes
Learning from the past	Learning from experiences from one's youth
Personal meaning of having cancer	Participants become aware of personal thoughts and emotions about having had cancer, with acknowledging of similarities and respect for differences in feelings and emotions
Support system	Exploration of available support; what kind of support is needed and how to get this kind of support; how to communicate with others to get the needed support
Saying goodbye	Emotions about having to say goodbye; going on by themselves
Planning for the future	How to hold on and being aware of what one has learned in the future

12 weeks intervention, occasionally, an expert was invited to give background information about a particular topic, such as nutrition or immune system.

Each session, with exception of the first and twelfth session, followed the same structure: Opening, discussion of the topic of that week, choosing next weeks' topic (see Box 1), closing of the session.

During the opening, the group leaders introduce the topic of that session and will shortly look back at the previous session. Other, for the participants' important subjects, could be discussed in a short round.

The central theme of the first session is introduction and getting to know each other. The group leaders introduce themselves and explain the aim of the social support group. Then the group members introduce themselves, giving them as much time as they need. The basic rules and the structure of the sessions are explained, and a topic for the next session is chosen.

In the twelfth session, the participants will evaluate the social support group and there will be much room to say goodbye to each other. Participants are offered the chance to discuss what they learned, what they missed and to give suggestions for improvement. They can also choose the topics of the two follow-up sessions.

Differences between group leaders

The therapists of the EE group psychotherapy were trained therapists, with several years of experience in leading this kind of therapy groups for people with cancer at the Helen Dowling Institute. They received extra training of one day, to become familiar with the study-objectives and with working along the lines of the manual.

The leaders of the social support groups were social workers or oncology nurses who were experienced in working with people with cancer and in working with groups. They received a training of one day in leading this specific social support group in which the study objectives, the structure of the group and the topics were explained, as well as how to handle these topics in the group setting. They could ask for support, intervision, supervision or any other kind of advise from the Comprehensive Cancer Center, Rotterdam.

Statistical analyses

Missing data on item level were imputed if no more than 25% of item scores for a particular subscale and a particular participant were missing and if a subscale consisted of at least four items. The mean score of the remaining item scores of the pertinent person on the subscale at stake was multiplied by the mean of the scores of the other participants on that particular item (column mean) and then divided by the overall mean of that subscale (row mean).

Because of the high ratio between dependent variables and the number of participants, we have tried to limit the number of variables in the analyses. Intercorrelation coefficients were determined for subscales of the POMS. Because of high intercorrelations, Principal Component Analyses were performed on the subscales of the POMS. This procedure has been described in more detail elsewhere [36].

Differences between the groups with regard to demographic and medical variables and with regard to the baseline values of psychosocial adjustment were tested with univariate analyses of variance (ANOVA) for the continuous data and Chi-square analyses for ordinal data.

The intervention effect was tested by using Random Regression Modeling (RRM). RRM allows to estimate the effect of time and type of intervention (psychotherapy group or social support group) and simultaneously to test the effect of age, type of surgery and stage of the disease on all outcome variables. RRM has many advantages above repeated measures ANCOVA and 'classical' regression analysis: It allows for missing data or an unequal number of data per subject, and for the inclusion of fixed and time varying covariates. Furthermore, a realistic covariance structure (as opposed to compound symmetry or independence between repeated measures) can be implemented [37]. All significant testing was fixed at $p = 0.05$ (two-tailed). For each outcome variable several models were tested. The first four tests concerned the effect of time. In the first series of model testing, the variable 'linear time trend' was being fixed (the slope of all individuals are equal). The second series of models encompassed in addition to linear time trend the variable quadratic time trend, which was entered as a fixed term. In the third and fourth series of tested models, the variable 'linear time trend' was incorporated

as being random (the slopes of all individuals are specific for each individual), while in the fourth series, the variable quadratic time trend was incorporated as a random term as well. The second set of four tests concerned the tests whether changes in time were different for the EE psychotherapy group condition and the social support group condition. To test the therapy effect, the same line as in the first four series of model testing was followed, with incorporation of the interaction term 'linear time trend x Type of intervention'. The maximum likelihood method was used to test which model fitted best. A model was decided to have a better fit, if the maximum likelihood was at least significant better than the previous model [37].

Results

Sample description

The investigators contacted two hundred and fifty one eligible women by telephone. Initially one hundred and four women (41.4%) agreed to participate in the intervention. These women were interviewed and finally 87 (34.7%) women enrolled into the study. The reasons for not participating of 164 women were: 1) not interested (n = 26), 2) having enough support (n = 26), 3) being too emotionally distressed (n = 14), 4) could not be reached by telephone (n = 19), 5) other reasons such as distance and time (n = 27), and 6) unknown (n = 52).

Of the 87 women who started the study, 67 women (77.0%) completed the study. Of the 20 women who dropped out, one woman had died, for two women attending a group became too emotional, three women were too ill to attend group meetings, for one woman the group meetings were not what she had expected, and thirteen women did not feel like participating anymore without giving further reasons. Women who stopped participating, were significantly older (53.2 years, SD = 7.21) than women who continued their participation (49.0 years, SD = 7.92). They did not differ on any other demographic, medical and psychosocial adjustment variables at baseline.

None of the 67 participants was diagnosed with distant metastases. Seventeen women had affected lymph nodes. Most participating women had had a mastectomy (65.7%). Three of them had had a reconstruction at the time of T0. The mean age was 49.0 years (range 29-68; SD 7.92). Most women had finished secondary school as their highest education (67.1%). Fifty one women had a partner, six of them were not living with their partner. Of the 15 women who were single, three were never married, ten were divorced and two women were widowed. Medical and demographic data of patients are summarized in Table 1.

Of the 67 participants, 33 women were randomly assigned to the EE group psychotherapy intervention and 34 women were randomly assigned to the social support group intervention. They did not differ on age, type of surgery, stage of the disease and psychological, psychosexual and social adjustment at baseline.

Table 1: Medical and demographic characteristics of patients (N=67)

	EE group therapy n	Social Support group n	Total %
Total patients	33	34	100.0
Mean time since surgery (weeks)	10.7	13.0	
Stage			
0	0	3	4.4
I	11	14	37.3
II	20	11	46.3
III	1	1	3.0
Missing	1	5	9.0
Number of affected lymph nodes			
0	23	26	73.1
1-4	6	7	19.4
>4	3	1	6.9
Missing	1	0	1.5
Type of surgery			
Breast conserving therapy	12	10	32.8
Mastectomy	21	24	67.2
Age (years)	49.0	49.4	
Highest education			
Primary school	2	2	6.0
Secondary school	21	26	70.1
Higher education	10	4	20.9
Missing	0	2	3.0
Marital status			
Partner	28	23	76.1
Single	5	10	22.4
Missing	0	1	1.5

The mean time between T0 and the start of the EE group psychotherapy was 14.1 weeks. The mean time between T0 and the start of the social support groups was 13.9 weeks. This difference was not significant.

At the end of the intervention, the mean number of attended sessions in the EE group psychotherapy group was 9.6, with 10 women attending all sessions and 3 women attending less than 2 sessions. The mean number of attended sessions in the social support group was 8.7. In this group 8 women did not miss any session and 3 women attended only 2 or less sessions. This difference was not significant.

Data reduction

Intercorrelation-coefficients were determined for the subscales of the POMS. Intercorrelations of the POMS-subscales were all statistically significant ($r \geq 0.35$). Therefore, a Principal Component Analysis with Varimax Rotation was performed on the subscales of the POMS, which resulted in two dimensions. The first dimension represents 'Distress' and is formed by

the subscales Depression, Anger and Tension. The second dimension is constructed by the subscales (reverse of) Fatigue and Vigour and represents 'Vitality'. For both components, the individual scores were calculated and used in the following analyses.

Changes over time

In the first series of testing, the effects of changes over time were tested. For all psychosocial adjustment indicators, with exception of Body Image, the best fitting model was the model in which the variable linear time trend was fixed. In the best fitting model for Body Image, linear time trend was incorporated as a random term.

Results show that there are no significant changes over time in Distress, Vitality, Sexual Functioning and Social Interactions (see Figure 1). Body Image and Recreation did change over time (see Figure 2): At the end of the study, women report a more positive body image than at the start of the study ($p \leq 0.001$). They also report that at the end of the study, their illness has less impact on their recreational activities ($p \leq 0.001$).

Of the biomedical variables, Type of Surgery was significantly related with Body Image ($p \leq 0.001$). Women with breast conserving therapy report a more positive body image than women who had mastectomy.

Effect of interventions

In the second series of model testing the effect of the interventions were tested. It was hypothesized that women participating in the EE group psychotherapy would report a greater improvement in psychosocial adjustment than women who participated in the social support groups. To test this hypothesis, the same models as in the first set of model testing were performed with the interaction term 'linear time trend x type of therapy' incorporated. Results of these analyses showed that for all psychosocial adjustment indicators, with exception of Body Image, the model in which linear time trend was incorporated as a fixed term, was

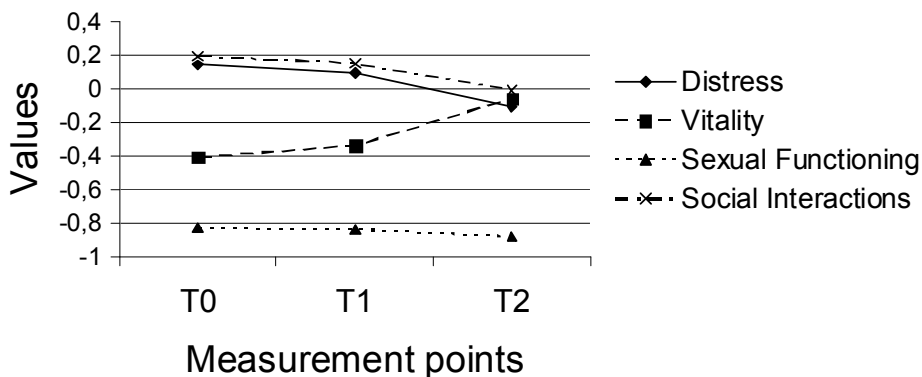


Figure 1: Changes over time for Distress, Vitality, Sexual Functioning and Social Interactions

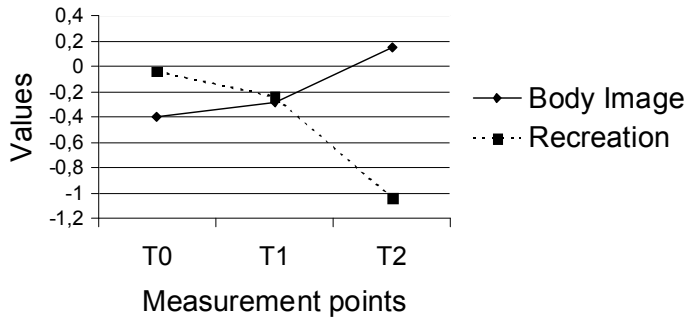


Figure 2: Changes over time for Body Image and Recreation

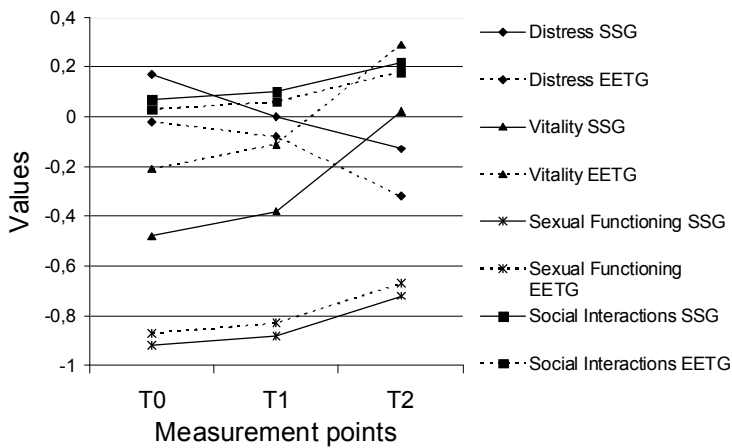


Figure 3: therapy effect for Distress, Vitality, Sexual functioning and Social Interaction

the best fitting model (see Figure 3). The best fitting model for Body Image was a model in which linear time trend was incorporated as a random term (see Figure 4). As in the previous set of model testing we found changes over time for Body Image and Recreation, but not for the other psychosocial adjustment indicators. For none of the psychosocial adjustment indicators did we find an effect of the intervention.

Discussion

The aim of the present study was twofold. First we tested whether participants of the two kinds of intervention programs were more psychosocially adjusted after one year follow-up compared to the start of the study. Secondly we hypothesized that women who participated in an EE group psychotherapy would benefit more from the intervention program than women who participated in a social support group intervention.

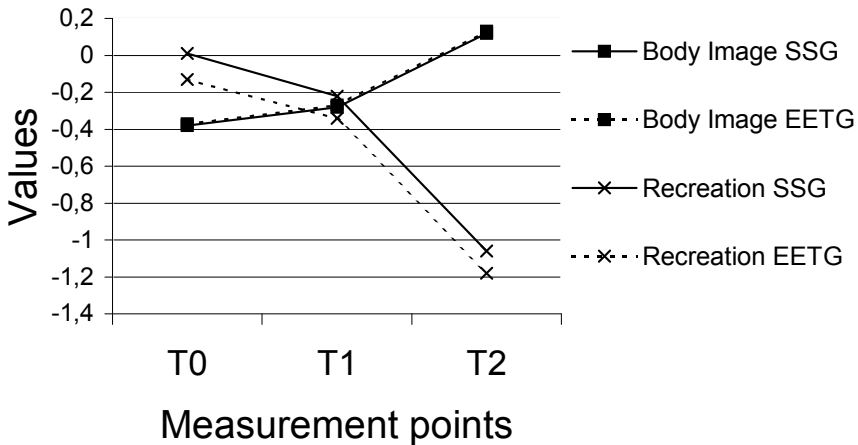


Figure 4: Therapy effect for Body Image and Recreation

The first hypothesis could only partly be confirmed. At one-year follow-up, there were no changes in Distress, Vitality, Sexual Functioning and Social Interactions. Positive changes were found for Body Image and Recreation. These findings seem to be contradicting with results of other intervention studies that report positive effects of the interventions on psychosocial adjustment [4,14,16,17,19,20,26,38]. However, positive results in the study of Samarel and co-workers (1997) concerned the control group as well and the results of Edelman and colleagues (1999) were no longer apparent at long-term [14,20]. Studies done by Berglund and co-workers (1994) [39] and Edmonds and co-workers (1999) [15] showed no significant effect of group interventions for women with breast cancer, although in the latter study, the therapist reported profound clinical changes [15]. Another study found mixed results: Participants of the group intervention improved when depression was concerned, but levels of distress remained the same [18].

Age and Stage of Disease were not related with any of the psychosocial adjustment indicators. Type of Surgery was related with Body Image in such a way that women who were treated with breast conserving therapy reported a more positive body image than did women who had mastectomy. This was an expected finding, since many studies already found this kind of relationship before [3,40].

We secondly expected that women who participated in the EE group psychotherapy would benefit more from the intervention than did women who participated in the social support groups. Results showed, however, that for none of the psychosocial adjustment indicators such a therapy effect existed. In the light of positive findings of other studies [27,41] this was a rather unexpected result. Bottomley and co-workers (1996) clearly found a more positive therapy effect for patients participating in a cognitive behavioral group therapy over those participating in a social support group condition [41], whereas Helgeson and colleagues

(1999) reports a stronger therapy effect for women in an education condition compared to women participating in a peer discussion group [27].

Results for supportive expressive therapy were mixed. Spiegel and colleagues [16,17,24] did report a positive therapy effect in women with breast cancer, while in other studies such an effect was not found [15,22]. Unfortunately, none of these studies included a social support group condition, which makes it impossible to be conclusive about the beneficial effect of this kind of therapy over social support groups.

The women in this study were at the start of this study as well psychosocially adjusted as women from the general population [36]. This is not in line with findings in many other studies, who found that about onethird of the women diagnosed with breast cancer show mild to moderate levels of psychosocial problems [1,2,42-44]. However, the group of women we studied were comparable to the group of women both Spiegel and co-workers (1999) [17] and Samarel and co-workers (1997) [20] studied.

From this study we can conclude that women with a primary breast cancer, who are psychosocially well adjusted at the start of the study do not especially benefit from a social support group intervention, nor from an EE group psychotherapy when the effect is measured with standardized questionnaires. We explored several reasons for not being able to find positive results in our study, where other studies report improvement in the same kind of women. Just like in the study of Edmonds and co-workers (1999), no changes could be measured with validated questionnaires [15]. However, the clinical impression of the interviews held with all participating women at T2, was that they had benefited from participating in a group: They had build a social network of women suffering the same illness, learned that the physical and emotional problems they encountered were not unusual and they felt less alone in their illness. Women who participated in the EE group psychotherapy also stated that they had learned more to express themselves. However, these topics were not asked in the used questionnaires.

We provided women with psychosocial counseling rather soon after surgery for primary breast cancer. This was to prevent them from becoming psychosocially maladjusted after some time. It was thought unethical to prevent women from participating in any of the two intervention groups for one and a half year, so no non-intervention control group was included in this study. Research in which women were followed for some time after breast cancer diagnosis without receiving special psychosocial care, report that 31% of these women show some kind of maladjustment after one year [45]. In fact, some of the studies who report positive therapy effects, contribute these effects in part to the decline in psychosocial adjustment in the control group [41,46]. Another reason why we did not find an effect of the intervention could be that the psychosocial adjustment level of the participating women in our study was in general comparable to normal, healthy women. Women in our study sample were already well adjusted at the start of the study and remained so at one year follow-up. In studies who reported positive therapy effects, participating women are very often suffering from at least

some emotional problems at the start of the study [14,17,19,41], whereas the mental status of participating women in studies with no effect was within the normal range [18] or unclear [16,27,39].

A final reason why we did not find positive results could be the stage of the illness of the participating women. Women in our study sample faced a primary breast cancer with good prognoses. Studies by Spiegel and co-workers ((1981) [24] and Van der Pompe (1997) [22] were done among women with metastatic breast cancer, who were facing death in the near future. Having good prognosis is often accompanied with questions of how to incorporate the experience of having cancer into one's life, while having to face death brings up questions about the meaning of life and saying definite goodbye to life, topics which are very well addressed in EE therapy. One could wonder whether this kind of therapy is recommended for the women in our study sample.

A limitation of this study is the number of participating women and the motivation for participation. In this study, only 27.5% of all approached women participated. This percentage confirms what is reported in other randomised intervention studies, which fully describe the number of eligible patients and the number of patients who completed the study [14,41,47]. Randomised studies with higher numbers do usually not describe how many eligible patients were sent a letter for participation or how many eligible patients were reached by other means initially [15,20,24,48]. These studies give, in our opinion an underscore of the real number of eligible patients. We stress, therefore, that the women in our study are representative for women who are diagnosed with breast cancer and are willing to participate in a psychological intervention program.

Implications for clinical practice

Although we did not found any effect in reducing psychosocial distress in women with a primary breast cancer, after participating in an EE psychotherapy group or a social support group, we would still recommend to offer these kinds of psychological counseling. From the interviews we held one year after the interventions were completed, it became clear that the women thought the interventions helpful. They realised that being slightly depressed sometimes or having feelings of mild anxiety at times, are normal reactions. They stated also that the support from other breast cancer patients was helpful even at longer times. We do recommend, however, to screen women on psychological aspects, before entering a psychological group intervention, instead of providing this kind of support to everyone. Further, it could very well be that the women in our study group rolled too fast after their surgery into this groups. We yield that offering this kind of psychological support leads to greater success when offered at a later stadium in the illness process.

References

1. Fallowfield L (1991). Counselling patients with cancer. In H. Davis & L. Fallowfield (Eds), *Counseling and Communication in Health Care*. John Wiley & Sons Ltd, 253-269
2. Irvine D, Brown B, Crooks D, Roberts J & Browne G (1991). Psychosocial adjustment in women with breast cancer. *Cancer*, 15: 1097-1117.
3. Kiebert GM, de Haes JCJM & van de Velde CJH (1991). The impact of breast conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*, 9: 1059-1070.
4. Helgeson VS & Cohen S (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15: 135-148.
5. Andersen BL (1992). Psychological interventions for cancer patients to enhance quality of life. *Journal of Consulting and Clinical Psychology*, 66: 552-556.
6. Trijsburg RW, van Knippenberg FCE & Rijpma SE (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine*, 54: 489-517.
7. Meyer TJ & Mark MM (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, 14: 101-108.
8. Cunningham AJ & Edmonds CVI (1996). Group psychological therapy for cancer patients: A point of view, and discussion of the hierarchy of options. *International Journal Psychiatry in Medicine*, 26: 51-82.
9. Fobair P (1997). Cancer support groups and group therapies: Part I. Historical and theoretical background and research on effectiveness. *Journal of Psychosocial Oncology*, 15: 63-81.
10. Leszcz M & Goodwin PJ (1998). The rationale and foundations of group psychotherapy for women with metastatic breast cancer. *International Journal of Group Psychotherapy*, 48: 245-273.
11. Edelman S, Craig A & Kidman AD (2000). Group interventions with cancer patients: Efficacy of psychoeducational versus supportive groups. *Journal of Psychosocial Oncology*, 18: 67-85.
12. Rehse B & Pukrop R (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: Meta-analyses of 37 published controlled outcome studies. *Patient Education and Counseling*, 50: 179-186.
13. Fawzy FI & Fawzy NW (1998). Group therapy in the cancer setting. *Journal of Psychosomatic Research*, 45:191-200.
14. Edelman S, Bell DR & Kidman AD (1999). A group cognitive behavior therapy programme with metastatic breast cancer patients. *Psycho-Oncology*, 8: 295-305.
15. Edmonds CVI, Lockwood GA & Cunningham AJ (1999). Psychological response to long term group therapy: A randomised trial with metastatic breast cancer patients. *Psycho-Oncology*, 8: 74-91.
16. Classen C, Butler LD, Koopman C, Miller E, DiMiceli S, Giese-Davis J, Fobair P, Carlson RW, Kraemer HC & Spiegel D (2001). Supportive-Expressive group therapy and distress in patients with metastatic breast cancer. A randomised clinical intervention trial. *Archives of General Psychiatry*, 58, 494-501.
17. Spiegel D, Morrow GR, Classen C, Raubertas R, Stott PB, Mudaliar N, Pierce HI, Flynn PJ, Heard L & Riggs G (1999). Group psychotherapy for recently diagnosed breast cancer patients: A multicenter feasibility study. *Psycho-Oncology*, 8: 482-493.
18. Antoni MH, Lehman JM, Kilbourn KM, Boyers AE, Culver JL, Alferi SM, Yount SE, McGregor BA, Arena PL, Harris SD, Price AA & Carver CS (2001). Cognitive-Behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology*, 20: 20-32.
19. Youssef FA (1984). Crisis intervention: A group-therapy approach for hospitalized breast cancer patients. *Journal of Advanced Nursing*, 9: 307-313.
20. Samarel N, Fawcett J & Tulman L (1997). Effect of support groups with coaching on adaptation to early stage breast cancer. *Research in Nursing and Health*, 20: 15-26.
21. Yalom ID (1980). *Existential Psychotherapy*. New York: Basic Books.
22. van der Pompe G (1997). *Mind-body interactions in breast cancer. Neuroendocrine and immune aspects of acute psychological stress and psychosocial intervention in breast cancer*. Dissertation, Leiden, The Netherlands.

23. Kissane DW, Bloch S, Miach P, Smith GC, Seddon A & Keks N (1997). Cognitive-existential group therapy for patients with primary breast cancer – techniques and themes. *Psycho-Oncology*, 6: 25-33.
24. Spiegel D, Bloom JR & Yalom I (1981). Group support for patients with metastatic cancer. *Archives of General Psychiatry*, 38: 527-533.
25. Goodwin PJ, Leszcz M, Ennis M, Koopmans J, Vincent L, Guthrie H, Drysdale E, Hundley M, Chochinov HM, Navarro M, Speca M & Hunter J (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *New England Journal of Medicine*, 345: 1719-1726.
26. Hosaka T (1996). A pilot study of structured psychiatric intervention for Japanese women with breast cancer. *Psycho-Oncology*, 5: 59-64.
27. Helgeson VS, Cohen S, Schulz R & Yasko J (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry*, 56: 340-347.
28. de Groot MH (1991) Psychometrische aspecten van een stemmingsschaal (verkorte POMS). *Gedrag en Gezondheid*, 20: 46-51.
29. Sprangers MAG, Groenvold M, Arraras JL, Franklin J, te Velde A, Muller M, Franzini L, Williams A, de Haes HCJM, Hopwood P, Cull A & Aaronson NK (1996). The EORTC Breast Cancer-Specific Quality of Life Module (QLQ-BR32): First results from a three-country field study. *Journal of Clinical Oncology*, 14: 2756-2768.
30. Osoba D, Aaronson N, Zee B, Sprangers M & te Velde A (1997). Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. *Quality of Life Research*, 6: 103-108.
31. Bergner M, Bobbit RA, Carter WB & Gilson BS (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19: 787-805.
32. Yalom ID & Greaves C (1977). Group therapy with the terminally ill. *American Journal of Psychiatry*, 134: 396-400.
33. Spiegel D & Bloom JR (1983). Group therapy and hypnosis reduce metastatic breast cancer pain. *Psychosomatic Medicine*, 45: 333-339.
34. Remie ME, Vos PJ, Maex E, Visser AP & Garssen B (1997). *Psychotherapeutische Begeleiding van Vrouwen met Borstkanker*. Internal report, Helen Dowling Institute, Rotterdam, The Netherlands.
35. Vos PJ & Remie ME (2001). Psychotherapeutische groupsbegeleiding voor vrouwen met borstkanker. In de Haes J.C.J.M., Gualthérie van Weezel L.M., Sanderman R. & van de Wiel H.B.M. (Eds.). *Psychologische Patiëntenzorg in de Oncologie. Handboek voor de Professional*. Assen, The Netherlands, Koninklijke Van Gorcum, 175-179.
36. Vos PJ, Garssen B, Visser AP, Duivenvoorden HJ & de Haes JCJM (2004). Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling. *Journal of Behavioral Medicine*, 27: 557-580.
37. Gibbons RD, Hedeker D, Elkin I, Wateraux C, Kraemer HC, Greenhouse JB, Shae MT, Imber SD, Sotsky SM & Watkins JT (1993). Some conceptual and statistical issues in the analysis of longitudinal psychiatric data. Application to the NIH treatment of Depression Collaborative Research Program dataset. *Archives of General Psychiatry*, 50: 739-750.
38. Samarel N, Tulman L & Fawcett J (2002). Effects of two types of social support and education adaptation to early stage breast cancer. *Research in Nursing and Health*, 25: 459-470.
39. Berglund G, Bolund C, Gustafsson U & Sjöden P (1994). A randomised study of a rehabilitation program for cancer patients: The 'starting again' group. *Psycho-Oncology*, 3: 190-201.
40. Moyer A (1997). Psychosocial outcomes of breast conserving surgery versus mastectomy: A meta-analytic review. *Health Psychology*, 16: 284-298.
41. Bottomley A, Hunton S, Roberts G, Jones L & Bradley C (1996). A pilot study of cognitive behavioural therapy and social support group interventions with newly diagnosed cancer patients. *Journal of Psychosocial Oncology*, 14: 65-83.
42. Greer S (1994). Psycho-oncology: It aims, achievements and future tasks. *Psycho-Oncology*, 3: 87-101.
43. Stiefel F & Razavi D (1994). Common psychiatric disorders in cancer patients. II Anxiety and acute confusional states. *Supportive Care in Cancer*, 2: 233-237.
44. Zabora J, Brintzenhofesoc K, Curbow B, Hooker C & Piantadosi S (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10: 19-28.

45. Maguire P (1995). Psychosocial interventions to reduce affective disorders in cancer patients: Research priorities. *Psycho-Oncology*, 4: 113-119.
46. Telch CF & Telch MJ (1986). Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. *Journal of Consulting and Clinical Psychology*, 54: 802-808.
47. Edgar L, Rosberger Z & Collet JP (2001). Lessons learned: Outcomes and methodology of a coping skills intervention trial comparing individual and group formats for patients with cancer. *International Journal of Psychiatry in Medicine*, 31: 289-304.
48. Cunningham AJ, Lockwood GA & Edmonds CV (1993). Which patients benefit most from a brief, group coping skills program? *International Journal of Psychiatry in Medicine*, 23: 383-398.

6

Dealing with early stage breast cancer: The effects of illness specific coping strategies on psychosocial well-being over time

Petra J. Vos

Adriaan P. Visser

Hugo J. Duivenvoorden

Bert Garssen

Hanneke C.J.M. de Haes

Abstract

In this study the relationship between dealing with a primary breast cancer in an illness specific way and psychosocial well being was studied. Sixtyseven women who were diagnosed with and had had surgery for primary breast cancer were recruited for a randomised intervention study. In this part of the study, the way women deal with the psychosocial consequences of breast cancer were studied. Participating women were questioned within 0 to 16 weeks after surgery (T1), at 3 months (T2) and one year after T2 (T3). The primary outcome measures were the relationships between Optimistic Attitude, Illness Orientated coping and Repressive coping on psychological functioning, sexual functioning and social functioning. Before the relationships were tested, the stability of both illness specific coping and psychosocial well-being over time was tested. Psychosocial well-being appears to be stable over time. Both optimistic attitude and repressive coping are stable over time as well. Illness orientated coping is not stable: Women who use this stratgy at the start of the study have changed it at T2 and T3. However, when women use illness orientated coping at T2, they still will use it at T3. It appears also that using an optimistic attitude is associated with most psychosocial well-being variables, in a way that women who tend to use this strategy report a better psychosocial well-being. Women who use illness orientated coping show less psychosocial well-being. Repressive coping appears not to be associated with most of the psychosocial well-being variables. By linking illness specific coping to psychosocial well-being, psychosocial counselors are provided information about which way of dealing with breast cancer should be discouraged and which coping strategies should be enhanced when providing women diagnosed with breast cancer psychosocial care.

Introduction

In several studies it has been suggested that the way breast cancer patients cope with the psychological, sexual and social consequences of being diagnosed with breast cancer is an important determinant of psychological distress [1-6]. These studies indicate that women who actively cope with breast cancer by trying to solve problems, searching for information or seeking social support [4,5], are better adjusted mentally than those who use avoidant strategies [1,3,5-8]. Which coping style is most helpful in psychological well-being, appears to depend on the stage of the disease. In their review, Harrison and Maguire (1994) conclude that in the acute phase of diagnosis and treatment, the use of avoidance is less anxiety provoking than a more active, information seeking coping style. They argue, however, that at longer term a change in the way one copes is necessary because of an increased risk of psychological morbidity [3]. However, Heim and colleagues (1997) found that women with breast cancer used the same coping style for several years. They also report that women with a less favourable coping style were less psychosocially adjusted than women using 'good' coping styles after some years [9].

In a review of Goldbeck (1997) results were that some denial results in positive mood regulation effects. This, he states, might be because denial, when not complete, might afford relief. It overlaps somewhat with positive attribution and give patients some sense of mastery over their situation [10]. Also Vos and de Haes (2007) reported that using denial is not always negative. It depends on the kind of used denial: Distractive strategies tend to reduce distress, while passive escape mechanisms appear to decrease psychosocial well-being [11].

In the abovementioned studies, coping is considered as a general attitude. In this approach, it is suggested that women who cope with a life-event one way, also tend to use this coping style when confronted with breast cancer. It is, however, also possible to measure the way women cope with breast cancer specifically. In an earlier part of this study, we found that illness specific coping strategies used by women confronted with breast cancer were significantly associated with psychosocial well-being, while generic coping strategies were only linked with some psychosocial indicators [12]. This suggested that although women's generic coping strategies could be helpful, the focus should be on the illness specific coping strategies women use in dealing with their breast cancer, a view shared with Nerenz and Leventhal (1983) [13].

Important attitudes and coping strategies in dealing with one's illness appear to be the patients' attitude toward the illness [14,15], patient's orientation of the illness (e.g. the constant awareness of having a (fatal) disease) and the strategy to repress feelings toward the illness [15].

In this part of the study, the relationship between illness specific coping and psychosocial well-being over time is tested. To test this relationship, we first study the course of the illness specific coping over time and the course of psychosocial well-being over time separately, in

order to be able to say something about the stability of the relationship between this kind of coping and psychosocial well-being over time. Based on our earlier findings [16,17] and other literature [14], we hypothesize firstly that an optimistic attitude is positive related with psychosocial well-being, since this coping strategy encompasses elements of self-control and also denial. Carver and colleagues (1993) reported that women with an optimistic attitude had lower distress [14].

A second hypothesis is that women who keep using an illness orientated coping style show more problems with psychosocial well-being over time. Women who used this kind of coping responses did report psychological problems at the start of this study [16]. Bleiker and co-workers (2000) also found that women with intrusive thoughts about the diagnosis had high levels of distress two years after being diagnosed with breast cancer [18].

Our final hypothesis is that women using an repressive coping strategy are psychosocially maladjusted at the start of the study, but that they become psychosocially well adjusted at follow-up. These kind of results were reported amongst experimental studies earlier [19-21].

Methods

Subjects and procedures

Patients were recruited from seven hospitals in the region of Rotterdam, The Netherlands. All ethical committees of the participating hospitals had given ethical approval of the current study. Eligible participants were women between 18 and 70 years of age, who had surgery for primary breast cancer no longer than four months ago at the time of the first contact, no distant metastases, sufficient knowledge of the Dutch language, and no psychiatric illness. An oncology nurse, who also judged the absence of psychiatric illness, informed them about the study. If a woman was not motivated to participate, she could indicate this by returning an answering-form. If not returned within three weeks, the investigator approached the women by telephone. If consent was given, an appointment was made for the first interview. During the interview women were asked to sign a written informed consent form and a set of questionnaires was handed over. Women were asked to complete these questionnaires at their earliest convenience. The first measurement (T1) took place between 0 and 16 weeks after having surgery. Three months later, the second measurement (T2) took place and the final measurement (T3) was one year after T2.

Measures

Medical and demographic data were obtained from a patient questionnaire, which obtained questions about size of tumor, date of diagnosis and surgery, type of surgery, number of affected lymph nodes, adjuvant therapy, age, education level and marital status. The referring oncology nurse checked the medical information in the medical records.

Psychosocial well-being was measured with 1) the Dutch version of the Profile of Moods States (POMS), containing the subscales Depression, Anger, Fatigue, Tension, and Vigour [22], 2) with the subscales Body Image and Sexual Functioning of the breast cancer specific module (QLQ-BR32) [23] of the EORTC QLQ-30 [24], and 3) with the subscales Recreation and Social Interactions of the Sickness Impact Profile (SIP) [25]. We choose these scales because the POMS contains both negative and positive affects, which we both also wanted to measure in this study. The reason for only the subscales sexuality and body image of the EORTC, was because we wanted this concept to be covered in our study, but we did not want to emphasis to much on it. There appeared, however, not a suitable questionnaire in Dutch to cover it the way we wanted these concepts to be covered. The reason why we did not choose the subscales about social issues from the EORTC as well, was because in our opinion, they were too small to cover the whole field of Social Interactions and Recreation as the SIP did.

Coping was measured with the – disease specific – Health and Diseases Inventories (HDI), which consists of the subscales *Optimistic Attitudes* in which persons who score high on this subscale have a self-confident and optimistic attitude towards life, enjoy life and have confidence in the future, and may act as if nothing has happened; *Illness Orientated Coping* indicating a preoccupation with what is happening in one's body and fostering a negative, fatalistic idea about the disease; and *Repressive Coping* showing non-expression of negative emotions, and asking for support and attention of others [26]. More information about the questionnaires used is given elsewhere [12,16].

Statistical analyses

Missing data on item level were imputed if no more than 25% of item scores for a particular subscale and a particular participant were missing and if a subscale consisted of at least four items. The mean score of the remaining item scores of the pertinent person on the subscale at stake was multiplied by the mean of the scores of the other participants on that particular item (column mean) and then divided by the overall mean of that subscale (row mean).

Because of the high ratio between dependent variables and the number of participants, we have tried to limit the number of variables in the analyses. Intercorrelation coefficients were determined for subscales of the POMS. Principal Component Analyses were performed on the subscales of the POMS due to the high intercorrelations of the POMS-scales. This resulted in two new dimensions. The first dimension represents 'Distress' and is formed by the subscales Depression, Anger and Tension. The second dimension is constructed by the subscales (reverse of) Fatigue and Vigour and represents 'Vitality'. For both components, the individual scores were calculated and used in the following analyses. The analyses of this data reduction exercises are described in more detail elsewhere [12].

The Structural Equation Modelling (SEM) approach was applied to explore the interrelationships of the variables [27]. This approach involves the examination of several models in order to identify the most plausible model and to estimate their individual parameters. The struc-

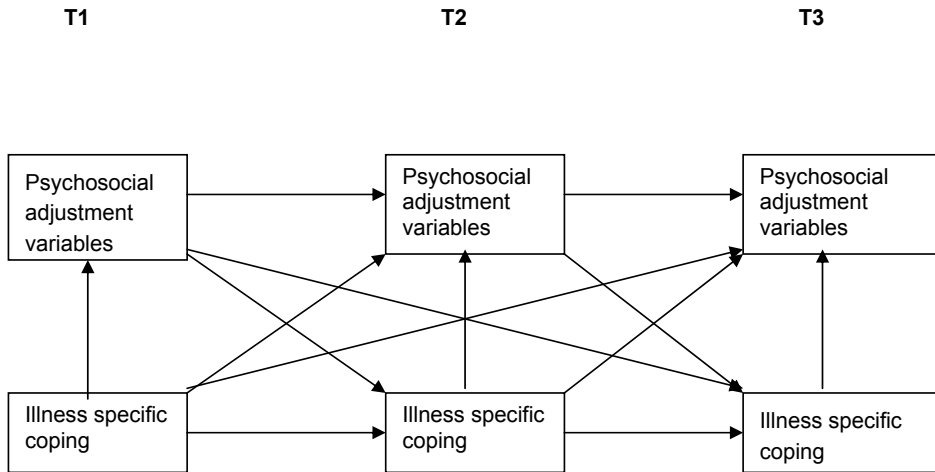


Figure 1: Hypothesized model

tural model concerns the direct and indirect relationships between independent variables (coping) and dependent variables (psychosocial well-being variables) [28]. As the number of patients was limited, only interrelationships of observed (manifest) variables were explored. The analyses for constructing structural equation models were conducted with the Mplus program [29].

The process of fitting SEM started with the construction of a theoretical based model (see Figure 1).

To find the most plausible model, several steps of model testing were performed. In the first step of model testing, the relationships between the illness specific coping scales on all measurement points were tested as well as the relationships between the psychosocial well-being variables at all measurement points. Also the influence of coping on the psychosocial well-being variables at baseline (T1) was tested.

In the second step, the first model was expanded with testing the influence of coping on the psychosocial well-being variables at T2. In the third model, the influence of coping on the psychosocial well-being variables at T3 was included.

In the next step, the previous model was expanded with the influence of coping at baseline at the psychosocial well-being variables at T2, while in the fifth step the influence of coping at T2 on psychosocial well-being variables at T3 was added.

In the sixth step of model testing, the model was expanded with the influence of the psychosocial well-being variables at baseline on coping at T2, and in the seventh step also the influence of the psychosocial well-being variables at T2 on coping at T3 were included.

The next step included testing the influence of coping at baseline on the psychosocial well-being variables at T3 and in the ninth and final step the influence of the psychosocial well-being variables at baseline on coping at T3 were tested.

For each model estimated, the fit was evaluated by examination of the individual parameter estimates, measures of overall fit and detailed assessment of fit (fitted and standardized residuals and modification indices). Different measures of goodness of fit are mentioned in the literature [27]. In this study, the following performance measures were selected to test the hypothesized models as was suggested by Martens (2005) [30]: 1) chi-square for model fit and p-value; 2) chi-square for model fit divided by degrees of freedom (a value of < 1.5 is acceptable); 3) Comparative Fit Index (CFI; a value of > 0.90 suggests a close fit, maximum value is 1.00) [31]; 4) Tucker-Lewis Index (TLI; a value of > 0.90 suggests a close fit, maximum value has to be 1.00) [32]; 5) root mean squares error of approximation (RMSEA; a value of 0.05 indicates a close fit) [33]; and 6) standardized root mean squares of residuals (SRMR; a value of < 0.05 indicates a good fit). The final model should be a model that fits the data of the sample reasonably well and in which all parameters are meaningful and substantively interpretable.

Results

Sample

Two hundred and fifty-one eligible women were first contacted by telephone, of which 87 (34,7%) women enrolled into the study. Of the 87 women who started the study, 67 women (77%) completed the study. Of the 20 women who dropped out, one women died, two women were too emotional to participate, three women were too ill, one women stopped because the study did not fulfil her expectations and thirteen women gave no reason for quitting the study.

Women who stopped participating, were significantly older (53.2 years, $SD = 7.2$) than women who continued their participation (49.0 years, $SD = 7.9$). They did not differ on any other demographic, medical and baseline variable.

None of the 67 participants was diagnosed with distant metastases. Seventeen women had affected lymph nodes. Most participating women had had a mastectomy (65.7%). Three of them had had a reconstruction at the time of T1. The mean age was 49.0 years (range 29-68; $SD 7.9$). Most women had finished secondary school as their highest education (67.1%). Fifty-one women had a partner, six of them were not living with their partner. Of the 15 women who were single, three were never married, ten were divorced and two women were widowed. Medical and demographic data are summarized in Table 1.

Best fitting model

The result of model testing are presented in Table 2. From this table, we can conclude that the hypothesized and final model we tested is the most plausible model

For the sake of clarity, the results of this model were divided in three parts.

Table 1: Medical and demographic characteristics

	N = 67	%
Mean time since surgery (weeks)	11.9	
Stage		
0	3	4.4
I	25	37.3
II	31	46.3
III	2	3.0
Missing	6	9.0
Number of affected lymph nodes		
0	49	73.1
1-4	13	19.4
>4	4	6.9
Missing	1	1.5
Type of surgery		
Breast conserving therapy	22	32.8
Mastectomy	45	67.2
Age (years)	49.2	
Highest education		
Primary school	4	6.0
Secondary school	47	70.1
Higher education	14	20.9
Missing	2	3.0
Marital status		
Partner	51	76.1
Single	15	22.4
Missing	1	1.5

Coping over time

From Figure 2 we learn that over time two of the three illness specific coping styles are stable: Women who tend to use an optimistic attitude or a repressive coping style at the start of the

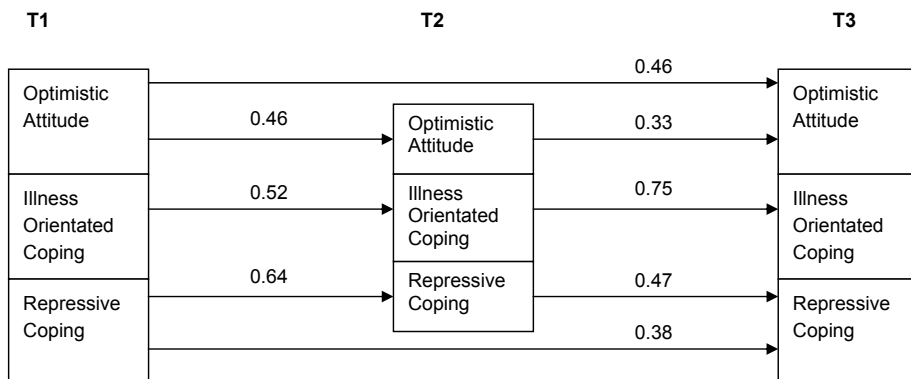


Figure 2: Stability of illness specific coping over time

Table 2: Results of models search: goodness of fit tests, psychosocial adjustment indicators

Models tested	X2	df	X2/df	p-val	CFI	TLI	RMSEA (95%)	SRMR
1. Psychosocial adjustment indicators at T0 are influenced by Coping at T0	355.70	234	1.50	0.000	0.896	0.845	0.077 (0.06-0.09)	0.127
2. Psychosocial adjustment indicators at T0 and T1 are influenced by Coping at T0 and T1 respectively	299.18	216	1.39	0.000	0.929	0.885	0.067 (0.05-0.08)	0.095
3. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively	295.42	216	1.37	0.000	0.932	0.890	0.065 (0.05-0.08)	0.083
4. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively; Psychosocial adjustment indicators at T1 are influenced by Coping at T0	274.24	198	1.39	0.000	0.935	0.885	0.067 (0.05-0.09)	0.079
5. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively; Psychosocial adjustment indicators at T1 and T2 are influenced by Coping at T0 and T1 respectively	261.92	180	1.46	0.000	0.930	0.864	0.072 (0.05-0.09)	0.078
6. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively; Psychosocial adjustment indicators at T1 and T2 are influenced by Coping at T0 and T1 respectively; Coping at T1 is influenced by Psychosocial adjustment indicators at T0	229.21	162	1.60	0.000	0.942	0.876	0.069 (0.05-0.09)	0.072
7. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively; Psychosocial adjustment indicators at T1 and T2 are influenced by Coping at T0 and T1 respectively; Coping at T1 and T2 is influenced by Psychosocial adjustment indicators at T0 and T1 respectively	191.01	144	1.33	0.005	0.960	0.903	0.061 (0.04-0.08)	0.060
8. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively; Psychosocial adjustment indicators at T1 and T2 are influenced by Coping at T0 and T1 respectively; Coping at T1 and T2 is influenced by Psychosocial adjustment indicators at T0 and T1 respectively; Psychosocial adjustment indicators at T2 are influenced by Coping at T0	167.15	126	1.33	0.008	0.965	0.903	0.061 (0.03-0.09)	0.058
9. Psychosocial adjustment indicators at T0, T1 and T2 are influenced by Coping at T0, T1 and T2 respectively; Psychosocial adjustment indicators at T1 and T2 are influenced by Coping at T0 and T1 respectively; Coping at T1 and T2 is influenced by Psychosocial adjustment indicators at T0 and T1 respectively; Psychosocial adjustment indicators at T2 are influenced by Coping at T0; Coping at T2 is influenced by Psychosocial adjustment indicators at T0	144.3	108	1.34	0.011	0.969	0.900	0.062 (0.03-0.09)	0.056

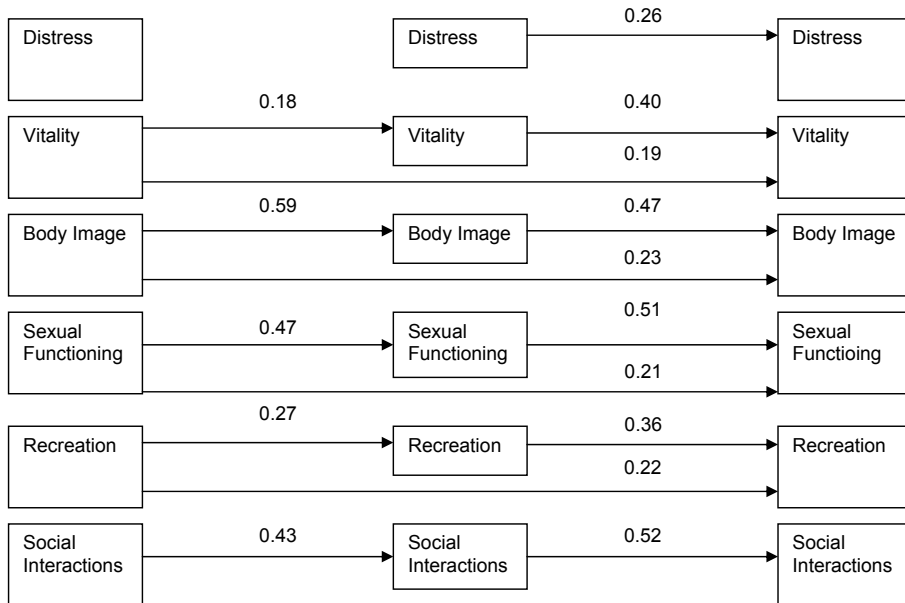


Figure 3 : Stability of psychosocial adjustment over time

study still do so at one year follow-up. No relationship between illness orientated coping at the start of the study and at follow-up exists, suggesting that women who use this kind of coping strategy at the start of the study shift to another coping strategy over time. However, women who use an illness orientated coping style both at T1 and T2 are inclined to use this style at one-year follow-up (T3) as well.

Changes in psychosocial well-being over time

The relationships between the psychosocial well-being variables over time are represented at Figure 3. Most of the variables are stable over time. However, no relationship exists between distress at T1 and distress at T2. The relationship between distress at T2 and at follow-up (T3) is significant, indicating that the level of distress varies across time.

Another finding is that the amount of social Interactions at the start of the study (T1) is not related with social interactions at T3.

Relationships between coping and psychosocial well-being

The significant relationships between coping and psychosocial well-being are shown in Figure 4. The relationships are represented in Table 3

Optimistic Attitude Using an optimistic attitude at T1 is related to having less distress, a positive body image and less problems with social interactions. The relationships between optimistic attitude and distress and body image are stronger at T2 and at T3.

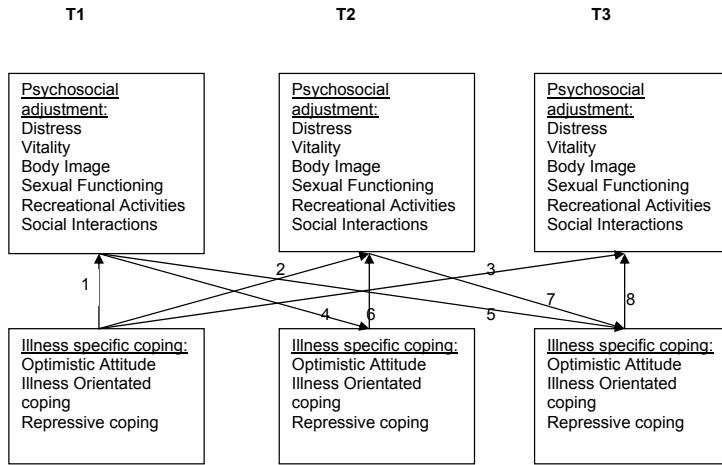


Figure 4: Relationships between psychosocial indicators and illness specific coping variables

Table 3 : Relationships between psychosocial indicators and illness specific coping

Arrows	Relation between :	Std	
1	Optimistic Attitude T1	- Distress T1	-0.22
	Optimistic Attitude T1	- Body Image T1	0.41
	Optimistic Attitude T1	- Social interactions T1	-0.42
	Illness Orientated coping T1	- Distress T1	0.43
	Illness Orientated coping T1	- Vitality T1	-0.22
	Illness Orientated coping T1	- Body Image T1	-0.24
	Repressive Coping T1	- Vitality T1	-0.27
2	Illness Orientated coping T1	- Vitality T2	-0.30
	Illness Orientated coping T1	- Recreation T2	0.28
	Repressive coping T1	- Vitality T2	-0.23
3	Illness Orientated coping T1	- Vitality T3	0.21
	Illness Orientated coping T1	- Recreation T3	-0.22
4	Distress T1	- Optimistic Attitude T2	0.28
	Sexual functioning T1	- Optimistic Attitude T2	-0.25
	Recreation T1	- Illness Orientated coping T2	-0.32
5	Sexual Functioning T1	- Optimistic Attitude T3	-0.18
6	Optimistic Attitude T2	- Distress T2	-0.52
	Optimistic Attitude T2	- Vitality T2	0.48
	Optimistic Attitude T2	- Body Image T2	0.24
	Optimistic Attitude T2	- Recreation T2	-0.35
	Optimistic Attitude T2	- Social Interactions T2	0.43
	Illness Orientated coping T2	- Vitality T2	0.36
7	Distress T2	- Illness orientated coping T3	-0.21
	Vitality T2	- Illness Orientated coping T3	-0.35
8	Optimistic Attitude T3	- Distress T3	-0.37
	Optimistic Attitude T3	- Vitality T3	0.27
	Optimistic Attitude T3	- Recreation T3	-0.26
	Illness Orientated coping T3	- Recreation T3	0.28
	Illness Orientated coping T3	- Body Image T3	-0.31
	Repressive Coping T3	- Social Interactions T3	0.36

At T2, using an optimistic attitude as a coping style is also related to more vitality, having less problems with recreational activities and less problems with social interactions.

At follow-up (T3), an optimistic attitude is related to having less problems in recreational activities.

Being distressed at T1 is related to having less of an optimistic attitude at T2. Having more sexual problems at the start of the study (T1) is associated to less use of an optimistic attitude at T2 and T3.

Illness orientated coping At T1 illness orientated coping is linked to more distress, less vitality and a negative body image. At T2 this kind of coping style is only related to less vitality, while at follow up (T3) an illness orientated coping strategy is linked to a negative body image.

Using an illness orientated coping style at T1 is also linked to more problems in performing recreational activities at both T2 and T3 and to less vitality at T3.

Being distressed and reporting more vitality at T2 appears to result in more use of an illness related coping strategy at T3. Having problems with recreational activities at T1 indicates more use of an illness orientated coping style at T2.

Repressive coping At T1 women who use a repressive coping strategy report less vitality. There are no relationships between a repressive coping style and any of the psychosocial well-being variables at T2, while at T3 using an repressive coping style is related to more problems in social interactions.

Finally, using an repressive coping style at T1 is linked with less vitality at T2.

Discussion

The course of illness specific coping styles and the stability of psychosocial well-being over time was studied. Women using optimistic attitudes or a repressive coping style at T1, were found to be inclined to continue to do so at one year follow up. Women using an illness orientated coping style were inclined to change this style at three months. However, if they still used this style after 3 months (T2) they were likely to use this strategy at one-year follow-up as well. We therefore conclude that in women with a primary breast cancer, the initially used illness specific coping styles are stable over time. This finding is in line with results reported by Carver and co-workers (1993) [14] and Nosarti and colleagues (2002) [34], although the latter also found that the initially used coping style diminished over time [34].

Psychosocial well-being appeared to be fairly stable over time as well. A remarkable finding in our study was that there was no relationship between distress at T1 and at T2, meaning that women, who were distressed at the start of the study, were much less distressed three months later. This finding is in line with other studies [18,35]. Women, on the other hand, who were distressed at T2, which was about four to seven months after surgery, were likely to be still distressed one year later, a result also reported by other researchers [35,36].

Social interactions were not stable across the study. Women reporting sufficient social interactions at the start of the study (T1) did not necessarily report sufficient social interactions at one-year follow-up. However, the amount of social interactions at the start of the study is significantly related to social interactions three months later, which is, again related with social interactions one year later. This suggest that there is only a slight shift in social interactions over the year, a finding confirmed by Hanson Frost and co-workers (2000), who found that newly diagnosed women reported more social problems than women with stable disease or with recurrent cancer [37].

A second aim of this study was to test the hypothesis that coping strategies of women with early stage breast cancer are linked with psychosocial well-being. We hypothesized that women who used an optimistic attitude would report better psychologically adjustment than women who did not use this coping style. We secondly hypothesized that women using an illness orientated coping strategy probably report worse psychosocially well-being. Both hypotheses were confirmed and these results are in line with the findings of others [2,4,9,38-42].

Our final hypothesis was that women who used a repressive coping style at the start of the study had a lower psychosocial well-being in the beginning, while their psychosocial well-being would improve later on. This hypothesis was not confirmed: Women using a repressive coping style experienced less vitality at the start of the study, and at follow-up report more problems with social interactions as a result of having breast cancer. There were no relations with the other psychosocial well-being variables. Apparently, repressive coping style in this group of women is not linked with psychosocial well-being. This result matches the findings of Muris and Merckelbach (1997) who suggest that repressive coping is seen as a maladaptive strategy [43], but it contradicts the theory of others [44,45] and the results of the study of Classen and co-workers (1996) who reported a positive mental well-being amongst women with breast cancer who used repressive coping strategies [46].

At the start of this part of the study, we decided to use illness specific coping strategies to be associated to psychosocial well-being, rather than generic coping strategies. Was this choice justified? We think it was. As was proven by this study, all coping styles were fairly stable over time, and it was also possible to link the chosen coping strategies to psychosocial well-being over time. By doing so, it gives psychosocial counselors information, which coping style should be enhanced and which coping strategy should be discouraged or changed, when providing psychosocial care for women with breast cancer. We suggest that illness specific coping is easier to deal with in counseling than generic coping will be, because illness specific coping is used only when confronted with this specific illness, while generic coping is a way of coping people use over time and situations.

A limitation of the present study could be the number of the participating women: 34,7% of all contacted women started in this study. Of these women, however, 77% has finished the study, which originally was an intervention study. These percentages confirm what is

reported in other randomised intervention studies, which fully describe how many eligible patients were approached and how many actually were rolled into the study. [40,48,49]. One could argue that these results are not generalisable to all women suffering from breast cancer, but that they are representative for women diagnosed with breast cancer who are willing to participate in a psychological intervention program. However, by using SEM to describe the course of illness specific coping and the stability of psychosocial well-being as well as the relationship between illness specific coping and psychosocial well-being, we were able to rule out the possible effects of the intervention. We thus argue that these results are also meaningful to other women suffering from a primary breast cancer without metastases, who do not intent to participate in any kind of intervention.

References

1. Weisman AD (1976). Early diagnosis of vulnerability in cancer patients. *American Journal of Medical Sciences*, 271: 187-196.
2. Friedman LC, Nelson DV, Baer PE, Lane M, Smith FE & Dworkin RJ (1992). The relationship of dispositional optimism, daily life stress and domestic environment to coping methods used by cancer patients. *Journal of Behavioural Medicine*, 15:127-141.
3. Harrison J & Maguire P (1994). Predictors of psychiatric morbidity in cancer patients. *British Journal of Psychiatry*, 65: 593-598.
4. de Groot K (1996). *Predicting Recovery from Surgery. The influence of Preoperative Stress and Mental Preparation on Postoperative State*, Dissertation, Erasmus Universiteit Rotterdam, The Netherlands.
5. Roesch SC & Weiner B (2001). A meta-analytic review of coping with illness. Do causal attributions matter? *Journal of Psychosomatic Research*, 50: 205-219.
6. Hack TF & Degner LF (2004). Coping responses following breast cancer diagnosis predict psychological adjustment three years later. *Psycho-Oncology*, 13: 235-247.
7. Friedman LC, Baer PE, Lewy A, Lane M & Smith FE (1988). Predictors of psychosocial adjustment to breast cancer. *Journal of Psychosocial Oncology*, 6: 75-94.
8. Greer S (1994). Psycho-oncology: It aims, achievements and future tasks. *Psycho-Oncology*, 3: 87-101.
9. Heim E, Valach L & Schaffner L (2004). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. *Psychosomatic Medicine*, 59: 408-418.
10. Goldbeck R (1997). Denial in physical illness. *Journal of Psychosomatic Research*, 43: 575-593.
11. Vos MS & de Haes JCJM (2007). Denial in cancer patients, an explorative review. *Psycho-Oncology*, 16: 12-25.
12. Vos PJ, Garssen B, Visser AP, Duivenvoorden HJ & de Haes JCJM (2004). Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling. *Journal of Behavioural Medicine*, 27: 557-580.
13. Nerenz DR & Levethal H (1983). Self regulation theory in chronic illness. In Burish T.G. & Bradley L.A. (Eds), *Coping with Chronic Diseases*. New York: Academic Press, 13-37.
14. Carver CS, Pozo C, Harris SD, Noriega V, Scheier MF, Robinson DS, Ketcham AS, Moffat FL & Clark KC (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personal and Social Psychology*, 65: 375-390.
15. Vos PJ, Visser AP, Garssen B, Duivenvoorden HJ & de Haes JCJM (2006). Effects of delayed psychosocial interventions versus immediate psychosocial interventions for women with early stage breast cancer. Is there a difference? *Patient Education and Counseling*, 60: 212-219.
16. Vos PJ, Garssen B, Visser AP, Duivenvoorden HJ & de Haes JCJM (2004). Psychosocial intervention for women with early stage breast cancer: A comparison between participants and a non-intervention group. *Psychotherapy and Psychosomatics*, 73: 276-285.
17. Vos PJ, Garssen B, Visser AP, Duivenvoorden HJ & de Haes JCJM (2007). Effectiveness group psychotherapy compared to social support groups in patients with early stage breast cancer. *Journal of Psychosocial Oncology*, 25: 37-60.
18. Bleiker MA, Pouwer F, van der Ploeg HM, Leer JWH & Adèr HJ (2000). Psychological distress two years after diagnosis of breast cancer: Frequency and prediction. *Patient Education and Counseling*, 40: 209-217.
19. Weinberger DA, Schwartz DA & Davidson RJ (1979). Low-anxious, high anxious and repressive coping styles: Psychometric patterns and behavioural and physiological responses to stress. *Journal of Abnormal Psychology*, 88: 369-380.
20. Boden JM & Dale KL (2001). Cognitive and effective consequences of repressive coping. *Current Psychology*, 20: 122-137.
21. Langens TA & Mörth S (2003). Repressive coping and the use of passive and active coping strategies. *Personality and Individual Differences*, 35: 46-73.
22. de Groot MH (1991). Psychometrische aspecten van een stemmingsschaal (verkorte POMS). *Gedrag en Gezondheid*, 20: 46-51.

23. Sprangers MAG, Groenvold M, Arraras JI, Franklin J, te Velde A, Muller M, Franzini L, Williams A, de Haes HCJM, Hopwood P, Cull A & Aaronson NK (1996). The EORTC Breast Cancer-Specific Quality of Life Module (QLQ-BR32): First results from a three-country field study. *Journal of Clinical Oncology*, 14: 2756-2768.
24. Osoba D, Aaronson N, Zee B, Sprangers M & te Velde A (1997). Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. *Quality of Life Research*, 6: 103-108.
25. Bergner M, Bobbit RA, Carter WB & Gilson BS (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19: 787-805.
26. de Bruin EJ & van Dijk M (1996). *Health and Disease Inventories. Een meetinstrument voor Aanpassingen aan Kanker. Handleiding*. Swets & Zeitlinger B.V. & Helen Dowling Instituut, The Netherlands
27. Hair JF, Anderson RE Tatham RL & Black WC (1998). *Multivariate Data Analysis. Fifth Edition*. Prentice-Hall Inc., New Jersey, USA.
28. Hoyle RH & Smith GT (1994). Formulating clinical research hypotheses as structural equation models: A conceptual overview. *Journal of Consulting and Clinical Psychology*, 62: 429-440.
29. Muthén LK & Muthén BO (1998). *Mplus. User's Guide*. CA Muthén & Muthén, Los Angeles.
30. Martens MP (2005). The use of structural Equation Modelling in counselling Psychology Research. *Counseling and Psychology*, 33: 269-298.
31. Bentler PM (1990). Comparative fit indexes in structural models. *Psychological Bulletin*, 107: 238-246.
32. Tucker LR & Lewis C (1973). A reliability coefficient for maximum likelihood factor analysis. *Psychometrika*, 38: 1-10.
33. Steiger JH (1990). Structural model evaluation and modification: An interval estimation approach. *Multivariate Behavioural Research*, 25: 173-180.
34. Nosarti C, Roberts JV, Crayford T, McKenzie K & David AS (2002). Early psychological adjustment in breast cancer patients. A prospective study. *Journal of Psychosomatic Research*, 53: 1123-1130.
35. Kayser K & Sormanti M (2002). A follow-up study of women with cancer: Their psychosocial well-being and close relationships. *Social Work and Health Care*, 35: 391-406.
36. Schroevers MJ, Ranchor AV & Sanderman R (2003). Depressive symptoms in cancer patients compared with people from the general population. The role of sociodemographic and medical factors. *Journal of Psychosocial Oncology*, 21: 1-26.
37. Hanson Frost M, Suman VJ, Rummons TA, Dose AM, Taylor M, Novotny P, Johnson R & Evans RE (2000). Physical, psychological and social well-being of women with breast cancer: The influence of disease phase. *Psycho-Oncology*, 9: 221-231.
38. Folkman S (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine*, 45: 1207-1221.
39. Schnoll RA, Harlow LL, Stolbach LL & Brandt U (1998). Structural model of the relationships among stage of the disease, age, coping and psychological adjustment in women with breast cancer. *Psycho-Oncology*, 7: 69-77.
40. Garssen B, de Haes H & Watson M (2000). Cancer. In Kapteyn A, Appels A. & Orth-Gomer K. (Eds), *Psychology in Medicine*. The Netherlands, Bohn Stafleu van Loghum, 119-135.
41. Kershaw T, Northouse L, Kritpracha C, Schafenacher A & Mood D (2004). Coping strategies and quality of life in women with advanced breast cancer and their family caregivers. *Psychology and Health*, 19: 139-155.
42. Wimberley SR, Carver CS & Antoni MH (2008). Effects of optimism, interpersonal relationships, and distress on psychosexual well-being among women with early stage breast cancer. *Psychology and Health*, 23: 57-72.
43. Muris P & Merckelbach H (1997). Suppression and dissociation. *Personality and Individual Differences*, 23: 523-525.
44. Meyers L (1997). Repressors responses to health related questionnaires. *British Journal of Health Psychology*, 2: 245-257.
45. Myers L, Brown CR & Power MJ (1998). Repressive coping and the directed forgetting of emotional material. *Journal of Abnormal Psychology*, 107: 141-148.
46. Classen C, Koopman C, Angell K & Spiegel D (1996). Coping styles associated with psychological adjustment to advanced breast cancer, *Health Psychology*, 15: 434-437.

47. Berglund G, Bolund C, Gustafsson U & Sjöden P (1994). A randomised study of a rehabilitation program for cancer patients: The 'starting again' group. *Psycho-Oncology*, 3: 190-201.
48. Edelman S, Bell DR & Kidman AD (1999). A group cognitive behaviour therapy programme with metastatic breast cancer patients. *Psycho-Oncology*, 8: 295-305.
49. Edgar L, Rosberger Z & Collet JP (2001). Lessons learned: Outcomes and methodology of a coping skills intervention trial comparing individual and group formats for patients with cancer. *International Journal of Psychiatry and Medicine*, 31: 289-304.

7

Summary and general conclusion

Introduction

In the past decades, there is a growing body of literature concerning the effects of psychosocial interventions for cancer patients. The scope of these interventions is broad: Some interventions focus on psycho-education [1-4], some on coping style [5-10], others on cognitive restructuring [11-14]. Also some interventions have been designed for cancer patients in general [15-21], some for patients with specific types of cancer [4,7,10,22-25], some for newly diagnosed cancer patients [10,12,26-28] some for patients with advanced disease [11,29-31] and some for cancer survivors [32-34].

The effectiveness of these interventions are studied in different ways. Some studies compare an intervention with a control group [13,35-38] while other studies compare two different types of intervention with each other [39-41]. In some studies patients are screened for case-ness before participating [13,14,35,42,43], in other studies this is not the case [2,12,38]. In some studies patients can choose in which intervention they would like to participate [35,39,43], while in other studies patients are randomly allocated to the intervention [3,6,9,37,38].

However, in the late '90s, when the current study started, the general impression from the literature was, that psychosocial interventions would help cancer patients to deal with the stresses (see Chapter 1) occurring after being diagnosed with cancer [8,15-17]. Based on these results and on the results of an earlier study performed at the Helen Dowling Institute among women with advanced breast cancer, the current study was designed. In the earlier study, women with advanced breast cancer were assigned to experiential-existential group psychotherapy. It turned out that only women who had high levels of distress at the start of the study reported beneficial effects of the intervention. The researcher recommended that a more direct comparison between different kinds of interventions should be carried out [11,44].

The present study

This study was a randomised controlled study in which women diagnosed with breast cancer without distant metastases were participating in one of two conditions: Group psychotherapy or a social support group. Women could participate if they had surgery in the past three weeks to four months. They were assigned to either group psychotherapy or a social support group and were randomised into a waiting-list condition, meaning that their intervention would start three months later.

The aim of the study was to investigate whether women who participate in any of these two conditions (i.e. group psychotherapy or social support group) would show a reduction in psychosocial problems. We expected this reduction to be more prominent in those women who participated in the group psychotherapy condition. A second aim of this study was to investigate what the effect of no treatment for three months and delayed intervention would be.

The outcomes we studied concerned psychological problems, psychosexual problems and social problems. Important factors, which we assumed might contribute to psychological outcome, were the amount of social support women experienced and the way women coped with their situation. Therefore, these factors were studied as well.

In total 251 women were contacted to participate in this study. Of these women, 104 women agreed to participate and 87 of them actually enrolled into the study. Of these 87 women, 67 completed the study.

Summary of the study

Chapter 1: Introduction

A short introduction is presented of the problems women encounter when diagnosed with breast cancer. These problems are divided into three areas: Psychological problems, sexual problems and social problems. Also, an outline for the current study is given.

Chapter 2: Level of adjustment

Offering psychosocial interventions shortly after diagnosis and surgery for breast cancer, is based on the assumption that women suffer most from psychological problems during this period. This assumption is justified, since several studies report that up to 56% of the women diagnosed with breast cancer report emotional problems initially [45-49]. These problems disappear in most women, though up to one third of the breast cancer patients still experience psychological problems after one year [50-53].

In the present study we started exploring the level of adjustment of the women participating and determining the relations between the various kind of variables, especially the baseline values of the outcome variables (distress, vitality, sexual functioning, body image, recreational activities and social interactions), the biomedical variables and the mediating variables coping and social support. We expected a relationship between psychosocial adjustment and medical and demographic factors in both a direct and an indirect way. Coping and social support were expected to be related to psychosocial adjustment, medical variables and demographic variables.

Results show that in general the women who participated in this study, were rather well adjusted. They were comparable to women of the general population. We further found that shortly after surgery especially illness specific coping is of high relevance for psychosocial adjustment, while generic coping (i.e. the way one copes generally with different kinds of daily stresses) was less relevant. Women who reported to have an optimistic attitude as a coping strategy, reported less depression, more vitality, a better body image, having more recreational activities and more social interactions. Women who used, on the other hand, an illness orientated coping style reported more distress and a negative body image, while

women who reported to use a more repressive coping style, experienced more distress and less vitality.

We also found that older women and women who had had a breast conserving therapy, used more often an optimistic attitude as their coping strategy. Not surprisingly, the latter group also reported a more positive body image. The positive role of social support often reported by others could not be confirmed.

In general, the findings of the baseline measurements were surprising. Especially the fact that the women who participated in this study did not suffer from more psychosocial problems than their healthy counterparts is important, because possibly of influence to therapy outcome

Chapter 3: Comparing the intervention and waiting-list condition

The next step in the study was comparing women who participated in the 12 weeks intervention to women who were on the waiting-list for the same kind of intervention. As the women in the waiting-list condition started with their intervention only three months later than the group who started immediately after enrolment into the study, we could only compare the short-term effects. Women were compared with respect to psychosocial adjustment, social support and coping.

At the start of the study, the intervention and waiting-list groups did not differ at demographic, medical and psychosocial adjustment (including coping and social support) variables. At the end of the study, women in the intervention groups did not differ from women on the waiting-list groups with respect to psychosocial adjustment and coping. It appeared that women who had participated in the social support group received more social support from non-significant others at the end of the intervention than women who had participated in the psychotherapy group or who were on the waiting-list. Another finding of this part of the study was that there was no significant change in psychosocial adjustment in women who participated in any of the intervention groups. We concluded that women diagnosed with breast cancer but without psychosocial problems after being diagnosed with breast cancer do not especially benefit from a short-term psychosocial intervention compared to women in a control group at short-term.

Chapter 4: The effects of delayed intervention

As half of the participating women were randomised into a waiting-list condition and receive the same type of intervention after the waiting period, the next step of this study was to investigate the effect of receiving delayed intervention compared to receiving immediate intervention. Comparisons were made just after completion of the intervention and at 6 months follow-up.

The main finding of this part of the study was that women in the delayed intervention condition were significantly more distressed at 6 months follow-up than women in the immediate

intervention condition. This finding suggests that women should be offered the possibility of participating in psychosocial intervention programs shortly after receiving surgery for breast cancer.

We also compared the pre- post- and follow-up measurements. As we also found in an earlier part of this study (see Chapter 3), pre-post changes did not occur, but at 6 months follow-up there was a change in body image and recreational activities in a positive direction. There was also a trend, indicating that women were less distressed and reported less social interactions at six months compared to the start of the study. However, these changes did not result from participating in any of the two intervention types, but from the passage of time.

Chapter 5: The effect of group psychotherapy and social support groups

The main aim of this study was to compare the effects of a social support group to experiential-existential (EE) group psychotherapy. We hypothesized that participants of both interventions would show a positive change in psychosocial adjustment, but that these changes would be more prominent in women who participated in the EE psychotherapy groups. The findings concerned the measurements just after completion of the intervention and at 12 months follow-up.

In agreement with previous findings, no changes in any of the psychosocial adjustment variables were shown. At 12-months follow-up, women of both intervention conditions reported an improvement in body image and in recreational activity. Apparently, the change reported in the previous part of the study at 6 months, was maintained at 12 months. However, no changes in any of the other psychosocial adjustment variables were found. Again, the reported changes were not the result of participating in any of the intervention conditions but of the passage of time.

Chapter 6: Illness specific coping in relation to psychosocial well-being

Finally, we studied the role of illness specific coping in relation to psychosocial well-being. We focussed on illness specific coping because this type of coping appeared to be more strongly related to psychosocial well-being than generic coping in an earlier part of this study [54].

We determined the stability of psychosocial well-being, of illness specific coping and the relationship between illness specific coping and psychosocial well-being over time. It appeared that both well-being and illness specific coping were fairly stable over time. It also appeared that women who use an optimistic attitude as a coping strategy reported more positive psychosocial well-being over time. Women, on the other hand, who tended to use illness orientated coping were more distressed and showed less psychosocial well-being. Women who used repressive coping strategies at the start of the study, report less vitality at that time. However, over time, there appeared to be no relationship between repressive coping and psychosocial well-being.

General conclusions and recommendations

The conclusion of this study is that the studied interventions, a social support group and experiential-existential group psychotherapy generally were not effective in reducing psychosocial problems in women suffering from a primary breast cancer without distant metastases. Neither changed these interventions maladaptive coping styles or increased social support. A result of this study was that 6 months and 12 months after completion of the intervention, body image has improved and women undertook more recreational activities compared to the start of the study. However, these outcomes were not the result of participating in any of the interventions, but the result of passage of time.

Results in perspective

When this study started in the late '90s, the conclusions of most intervention studies were that psychosocial interventions for cancer patients would reduce psychosocial problems such as depression and anxiety [15-17]. In these studies, participants were sometimes selected on the basis of high levels of psychological problems at the start [14,35,42], some studies did not apply randomisation [6,14,27,35,42], the used intervention programs were not always clear [27,28,35,42] or very specific [14]. As a consequence, it was easier to gain positive results, implying that psychological interventions for cancer patients were effective.

After 1995, other researchers started intervention programs as well. Our review of the recent literature showed that in the past five years, several randomised intervention studies among women with breast cancer have been carried out [55-67]. Of these studies, only one study compared more than one kind of intervention [61]. All other interventions were compared to a control group receiving standard care, with some of these control groups receiving additional information [56,59,64-66]. The numbers of participants in these intervention studies were in general somewhat higher than in our study, varying from 66 [55] to 259 participants [56]. In some studies women with early stage breast cancer were studied, while in others women with advanced breast cancer [60,64,65] were studied. Most interventions were different from the type of intervention we carried out [55,57-60,62-64]. From the studies, which studied a comparable type of intervention, results were indeed comparable to our results: There was no significant change in distress in the intervention condition [56,61,65,67]. Kissane and colleagues (2003), reported in one study that although there was no change in distress, participants of the intervention condition reported a slight positive change in anxiety [56]. In a later study, Kissane and co-workers (2007) found that there was a positive change in social functioning, but no change in distress when the entire study group was taken into account. However, women who were at the start of this study at risk for developing depression, appeared to be improved at the end of the study [65].

The study of Chan and co-workers (2007) compared three intervention types: a Body-Mind-Spirit intervention, a supportive-expressive group intervention, which is comparable to our

therapy groups, and a self help social support group. The supportive expressive therapy group, showed no change in distress. Nor did the social support group [61]

In a series of meta-analyses published in 2006 [68], the effectiveness of psychological interventions for cancer patients is even questioned. The conclusions of Coyne and co-workers (2006) are not very optimistic. They state that 1) earlier published reviews were often narrative reviews in stead of systematic analyses of randomised trials, 2) non-randomised trials report more positive effects than randomised trials, 3) when no quality control was performed, effects turned out to be larger than in case quality control was applied, and 4) if only published studies are included, effectiveness is more often demonstrated than when non-published studies are included [69]. This negative opinion is not shared by Manne and Andrykowski (2006), who found at least five well designed randomised controlled trials [57,70-73] with positive effects [74].

Reviews published after 2002 show only minimal effect, especially with respect to reduction of depression [31,20,75]. Ross and colleagues [75] concluded after reviewing the literature, that the effectiveness of interventions remains unresolved, and Edwards and co-workers [31] concluded that there is not enough evidence to promote group psychosocial therapies (based on cognitive behavioral or supportive expressive premises) for women diagnosed with metastatic breast cancer. They concluded that the benefits of the interventions are only proven for some psychosocial outcomes and are only for short-term effects [31]. Newell and colleagues [20] concluded after an extensive literature search that it is not possible to recommend for or against psychosocial interventions. They found that most recommendations are only based on one or two fair-quality trials, making it difficult to state that psychosocial interventions are recommended for all cancer patients. Interestingly, however, in their meta-analysis the effect of group interventions was more evident than the effect of other psychosocial interventions.

In a review of psychoeducational interventions, it was reported that two third of the interventions were effective in reducing depression in adult cancer patients [76]. However, of the effective intervention studies, only one third were randomised controlled trials with more than 100 patients. Whether the remaining intervention studies were randomised controlled trials, remains unclear from the review. Taken things together, unfortunately, the effectiveness of psychosocial interventions among (breast) cancer patients is far from evident yet.

Study limitations

This study has some limitations. The women in our study were diagnosed with a primary breast cancer without distant metastases and had a rather good prognosis. It might well be that when the prognosis is worse, the interventions studied are more effective: In such case, women are struggling to survive or are bound to make some final decisions in their lives. Furthermore, most women in our study reported at the start of the study that they were not suffering from serious psychosocial problems. This is a problem if one tries to demonstrate

a reduction of distress in an intervention study. We would strongly suggest, therefore, that women should be screened for psychological problems first before invited them to participating in a psychosocial intervention study.

Another shortcoming of this study could be the selection of the questionnaires used. Although all questionnaires were reliable and most of them validated, they might not be sensitive enough to detect a change in our study group as a whole. However, this does not mean that these questionnaires should not be used in future research. The POMS [77] for example, has been proven to be useful in other kind of research and with other groups of patients [78-80]. Apart from that, some of these questionnaires could well be used in hospitals for screening patients or for monitoring the psychological status of patients. An example is the EORTC [81,82]. This questionnaire could be used in hospitals to monitor the quality of life of cancer patients in several areas (psychological, social, sexual, cognitive etc.) at different time points during treatment.

In our study, women could not choose in which kind of intervention they would participate. They also could not choose when they wanted to start with their intervention. This means that, at least partly, the interventions were not tailored to their individual needs. This is an obvious result of the randomised study design, but it could have influenced the outcome of it as well.

A final shortcoming of this study was that there was no real control group. When we started this study, findings of other intervention studies were positive and it was thought unethical to withhold something 'good' from women who were diagnosed with breast cancer for the 15 months' duration of the study. Especially since not being able to participate in any of the intervention groups was not a free choice but part of the randomisation process. In future research we would strongly recommend the inclusion of a no-treatment control group as some decrease in distress is expected in a non-intervention group. It could well be that being in any of the intervention groups prevented women from becoming distressed over time, because they learned how to deal with the stresses of having had breast cancer. In case a control group is included in this kind of study, women who are in the control groups should be monitored carefully, so that when psychosocial problems arise before the end of the study, they are offered psychosocial help.

Opportunities

From our study it could be concluded that women who participated in any of the intervention groups did not find the groups beneficial. However, this was not the case. Although there was not a result in the sense that they were psychosocially better adjusted at the end of the study compared to the start, women valued both interventions highly. Just after completion of the intervention and at 12 months follow up, we have asked women to value the intervention they had participated in. We asked them about the quality of the intervention, whether they would recommend this kind of intervention to other women, if they felt that the intervention

Table 1: How women valued the intervention

Subject	Therapy group		Social support group	
	After completion	At follow-up	After completion	At follow-up
Quality of intervention	3.13	3.34	3.37	3.53
Recommend to others	3.50	3.69	3.55	3.88
Did the intervention help	3.47	3.63	3.45	3.85
Satisfied	3.70	3.78	3.77	3.94
Would you come back	3.40	3.66	3.47	3.85
Mark	8,06	7.77	8.17	7.79

had helped them, if they were satisfied with the intervention and if they would come back to participate in the same kind of intervention in case they needed to. Women could answer on a scale from 1 (very bad) to 4 (very good). We also asked them to rate the intervention with a number between 0 (very bad) and 10 (very good). The findings are presented in Table 1.

Scores on the 0 to 4 scale were 3 and 4 and were 7.8 and 8.1 on the 0 to 10 scale. In other words, participating women valued both interventions highly. There was no significant difference between the appreciation of the psychotherapy groups and the social support groups. Over time the members of the support groups valued the quality of the intervention better ($p = 0.032$). Chan and colleagues (2007) and Classen and co-workers (2008) also reported that they found no evidence of reduction in distress as a result of a supportive-expressive intervention program for women diagnosed with breast cancer but they also found that women valued the intervention as helpful [61,67].

Based on the results of our study and the high values of the women who participated in this study, we have some recommendations. Women need to know that if they need psychosocial support at any time in their illness process, it is possible to receive such assistance and where to get it. This applies to all women falling into the normal range of psychosocial adjustment. It does not mean that there is not a task for hospitals. Hospital staff should screen all women diagnosed with breast cancer on psychosocial adjustment and women who are at risk for developing psychosocial problems should be offered psychosocial help in a more proactive way. To test such approach, we recommend a 'watchful-waiting' study. In this kind of study, which should be randomised, women will be assigned to one of two conditions. In the first condition women participate in a psychosocial intervention group shortly after diagnosis (1–3 months). Women assigned to the second condition are regularly (every 1 or 2 months) monitored and start with the same intervention when the scores of the screening instrument indicates that psychological problems exist. In this way it is tested whether offering interventions when psychosocial support is needed is more effective than offering interventions to all women diagnosed with breast cancer.

References

1. La Fortune Fredette S & Beattie M (1986). Living with cancer. A patient education program. *Cancer Nursing*, 9: 308-316.
2. Berglund G, Blund C, Gustafsson UL & Sjöden PO (1994). A randomised study of a rehabilitation program for cancer patients: The 'starting again' group. *Psycho-Oncology*, 3: 109-120.
3. Samarel N, Tulman L & Fawcett J (2002). Effects of two types of social support and education on adaptation to early stage breast cancer. *Research in Nursing & Health*, 25: 459-470.
4. Rosberger Z, Edgar L, Collet JP & Fournier MA (2002). Patterns of coping in women completing treatment for breast cancer: A randomised controlled trial for NuCare, a brief psychoeducational workshop. *Journal of Psychosocial Oncology*, 20: 19-37.
5. Telch CF & Telch MJ (1986) Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. *Journal of Consulting and Clinical Psychology*, 54: 802-808.
6. Cunningham AJ, Lockwood GA & Edmonds CL (1993). Which cancer patients benefit most from a brief, group coping skills program? *International Journal of Psychiatry in Medicine*, 23: 383-398.
7. Fawzy FI, Fawzy NW & Hyun CS (1994). Short-term psychiatric intervention for patients with malignant melanoma: Effects on psychological state, coping and the immune system. In Lewis C.E., O'Sullivan C. and Barraclough J. (Eds) *The Psychoimmunology of Cancer. Mind and Body in the Fight for Survival*, Oxford, Oxford Medical Publ. 291-319.
8. Heim E (1995). Coping based intervention strategies. *Patient Education and Counseling*, 26: 145-151.
9. Edgar L, Rosberger Z & Collet JP (2001). Lessons learned: Outcomes and methodology of a coping skills intervention trial comparing individual and group formats for patients with cancer. *International Journal of Psychiatry in Medicine*, 31: 289-304.
10. Owen JE, Klapow JC, Roth DL, Shuster JL, Bellis J, Meredith R & Tucker DC (2005). Randomized pilot of a self-guided internet coping groups for women with early-stage breast cancer. *Annals of Behavioural Medicine*, 30: 54-64.
11. van der Pompe G, Antoni MH, Visser A & Garssen B (1996). Adjustment to breast cancer: The psychobiological effects of psychosocial interventions. *Patient Education and Counseling*, 28: 209-219.
12. Antoni MH, Lehman JM, Kilbourn KM, Boyers AE, Culver JL, Alferi SM, Yount SE, McGregor BA, Arena PL, Harris SD, Price AA & Carver CS (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early stage breast cancer. *Health Psychology*, 20: 20-32.
13. Edelman S, Bell DR & Kidman AD (1999). A group cognitive behaviour therapy programme with metastatic breast cancer patients. *Psycho-Oncology*, 8: 295-305.
14. Bottomley A, Hunton S, Roberts G, Jones L & Bradley C (1996). A pilot study of cognitive behavioural therapy a social support group interventions with newly diagnosed cancer patients. *Journal of Psychosocial Oncology*, 14: 65-83.
15. Anderson BL (1992). Psychological interventions for cancer patients to enhance the quality of life. *Journal of Consulting and Clinical Psychology*, 66: 552-568.
16. Trijsburg RW, van Knippenberg FCE & Rijpma SE (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine*, 54: 489-517.
17. Meyer TJ & Mark MM (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, 14: 101-108.
18. Fawzy FI & Fawzy NW (1998). Group therapy in the cancer setting. *Journal of Psychosomatic Research*, 45: 191-200.
19. Sheard T & Maguire P (1999). The effect of psychological interventions on anxiety and depression in cancer patients: Results of two meta-analyses. *British Journal of Cancer*, 80: 1770-1780.
20. Newell SA, Sanson Fisher RW & Savolainen NJ (2002). Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute*, 94: 558-584.

21. Rehse B & Pukrop R (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: Meta analysis of 37 published controlled outcome studies. *Patient Education and Counseling*, 50: 179-186.
22. Jacobs C, Ross RD, Walker IM & Stockdale FE (1983). Behavior of cancer patients: A randomized study of the effects of education and peer support groups. *American Journal of Clinical Oncology*, 6: 347-350.
23. Houts PS, Whitney CW, Mortel R & Bartholomew MJ (1986). Former cancer patients as counselors of newly diagnosed cancer patients. *Journal of the National Cancer Institute*, 76: 793-796.
24. Pinto BM, Clark MM, Maruyama NC & Feder SI (2003). Psychological and fitness changes associated with exercise participation among women with breast cancer. *Psycho-Oncology*, 12: 118-126.
25. Carlson LE, Specia M, Patel KD & Goodey E (2004). Mindfulness-based stress reduction in relation to quality of life, mood, symptoms of stress, and immune parameters in breast and prostate cancer outpatients. *Psychosomatic Medicine*, 65: 571-581.
26. Kaufman E & Micha VG (1987). A model for psychotherapy with the good-prognosis cancer patient. *Psychosomatics*, 28: 540-548.
27. Hosaka T, Sugiyama Y, Hirai K, Okuyama T, Sugawara Y & Nakamura Y (2001). Effects of modified group intervention with early-stage breast cancer patients. *General Hospital Psychiatry*, 23: 145-151.
28. Puig A, Lee SM, Goodwin L & Sherrard PAD (2006). The efficacy of creative arts therapy to enhance emotional expression, spirituality, and psychological well-being of newly diagnosed stage I and stage II breast cancer patients: A preliminary study. *The Arts in Psychotherapy*, 33: 218-228.
29. Spiegel D & Bloom JR (1983). Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosomatic Medicine*, 45: 333-339.
30. Goodwin P, Leszcz M, Ennis M, Koopmans J, Vincent L, Guther H, Drysdale E, Hundelby M, Chochinov HM, Navarro M, Specia M & Hunter J (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *The New England Journal of Medicine*, 345: 1719-1726.
31. Edwards AGK, Hailey S & Maxwell M (2005). Psychological interventions for women with metastatic breast cancer. *The Cochrane Library*, 2.
32. Stalker MZ, Stewart Johnson P & Cimma C (1989). Supportive activities requested by survivors of cancer. *Journal of Psychosocial Oncology*, 7: 21-31.
33. Gellert GA, Maxwell RM & Siegel BS (1993). Survival of breast cancer patients receiving adjunctive psychosocial support therapy: A 10-year follow-up study. *Journal of Clinical Oncology*, 11: 66-69.
34. Spiegel D (1995). How do you feel about cancer now? -- Survival and psychosocial support. *Public Health Reports*, 110: 298-300.
35. Youssef FA (1984). Crisis intervention: A group-therapy approach for hospitalised breast cancer patients. *Journal of Advanced Nursing*, 9: 307-313.
36. Samarel N, Fawcett J & Tulman L (1997). Effect of support groups with coaching on adaptation to early stage breast cancer. *Research in Nursing and Health*, 20:15-26.
37. Edmonds CVI, Lockwood GA & Cunningham AJ (1999). Psychological response to long term group therapy: A randomised trial with metastatic breast cancer patients. *Psycho-Oncology*, 8: 74-91.
38. Classen C, Butler LD, Koopman C, Miller E, DiMiceli S, Giese-Davis J, Fobair P, Carlson RW, Kraemer HC & Spiegel D (2001). Supportive-Expressive group therapy and distress in patients with metastatic breast cancer. A randomised clinical intervention trial. *Archives of General Psychiatry*, 58: 494-501.
39. Hosaka T (1996). A pilot study of structured psychiatric intervention for Japanese women with breast cancer. *Psycho-Oncology*, 5: 59-64.
40. Helgeson VS, Cohen S, Schulz R, & Yasko J (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry*, 56, 340-347.
41. Samarel N, Tulman L & Fawcett J (2002). Effects of two types of social support and education adaptation to early stage breast cancer. *Research in Nursing and Health*, 25: 459-470.
42. Tarrier N & Maguire P (1984). Treatment of psychological distress following mastectomy: An initial report. *Behavioral Research and Therapy*, 22: 81-84.
43. Spiegel D, Morrow GR, Classen C, Raubertas R, Stott PB, Mudaliar N, Pierce HI, Flynn PJ, Heard L & Riggs G (1999). Group psychotherapy for recently diagnosed breast cancer patients: A multicenter feasibility study. *Psycho-Oncology*, 8, 482-493.

44. Pompe van der, G. (1997). *Mind-body interactions in breast cancer. Neuroendocrine and immune aspects of acute psychological stress and psychosocial intervention in breast cancer*. Dissertation, Leiden, The Netherlands.
45. Fallowfield L (1991). Counselling patients with breast cancer. In Davis H. & Fallowfield L. (Eds). *Counselling and Communication in Health Care*. John Wiley & Sons Ltd, 253-269.
46. Kiebert GM, de Haes JCJM & van de Velde CJH (1991). The impact of breast conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*, 9: 1059-1070.
47. Greer S (1994). Psycho-oncology: It aims, achievements and future tasks. *Psycho-Oncology*, 3: 87-101.
48. Spiegel D (1997). Psychosocial aspects of breast cancer treatment. *Seminars in Oncology*, 24: S1-36 - S1-47.
49. van 't Spijker A, Trijsburg RW & Duivenvoorden HJ (1997). Psychological sequale of cancer diagnosis: A meta-analytical review of 58 studies after 1980. *Psychosomatic Medicine*, 59: 280-293.
50. Morris T (1979). Psychological adjustment to mastectomy. *Cancer Treatment Reviews*, 6: 41-61.
51. Hughson AVM, Cooper AF, McArdle CS & Smith DC (1988). Psychosocial consequences of mastectomy, levels of morbidity and associated factors. *Journal of Psychosomatic Research*, 32: 383-391.
52. Goldberg JA, Scott RN, Davidson PM, Murray GD, Stallard S & Maguire GP (1992). Psychological morbidity in the first year after breast surgery. *European Journal of Surgical Oncology*, 18: 327-331.
53. Bleiker EMA, Pouwer F, van der Ploeg HM, Leer JWH & Ader HJ (2000). Psychological distress two years after diagnosis of breast cancer: Frequency and prediction. *Patient Education and Counseling*, 40: 209-217.
54. Vos PJ, Garssen B, Visser AP, Duivenvoorden HJ & de Haes JCJM (2004). Early stage breast cancer: Explaining level of psychosocial adjustment using Structural Equation Modelling. *Journal of Behavioral Medicine*, 27: 557-580.
55. Heiney SP, McWayne J, Hurley TG, Lamb LS, Bryant LH, Butler W & Godder K (2003) Efficacy of therapeutic group by telephone for women with breast cancer. *Cancer Nursing*, 26: 439-447.
56. Kissane DW, Bloch S, Smith GC, Miach P, Clarke DM, Ikin J, Love A, Ranieri N & McKenzie D (2003). Cognitive-existential group psychotherapy for women with primary breast cancer: A randomised controlled trial. *Psycho-Oncology*, 12: 532-546.
57. Manne SL, Ostroff JS, Winkel G, Fox K, Generosa G, Miller E, Ross S & Frazier T (2005). Couple-focused group intervention for women with early stage breast cancer. *Journal of Consulting and Clinical Psychology*, 73: 634-646.
58. Scheier MF, Helgeson VS, Schulz R, Colvin S, Berga S, Bridges MW, Knapp J, Gerszten K & Pappert WS (2005). Interventions to enhance physical and psychological functioning among younger women who are ending nonhormonal adjuvant treatment for early-stage breast cancer. *Journal of Clinical Oncology*, 23: 4298-4311.
59. Antoni MH, Wimberly SR, Lechner SC, Kazi A, Sifre T, Urcuyo KR, Phillips K, Smith RS, Petronis VM, Guellati S, Wells KA, Blomberg B & Carver CS (2006) reduction of cancer-specific thought intrusions and anxiety symptoms with a stress management intervention among women undergoing treatment for breast cancer. *American Journal of Psychiatry*, 163: 1791-1797.
60. Aranda S, Schofield P, Weih L, Milne D, Yates P & Faulkner R (2006). Meeting the support and information needs of women with advanced breast cancer: A randomised controlled trial. *British Journal of Cancer*, 95: 667-673.
61. Chan CL, Ho RT, Lee PW, Cheng JY, Leung PP, Foo W, Chow LW, Sham JS & Spiegel D (2006). A randomised controlled trial of psychosocial interventions using the psychophysiological framework for Chinese breast cancer patients. *Journal of Psychosocial Oncology*, 24: 3-26.
62. Andersen BL, Farrar WB, Golden-Kreutz D, Emery CF, Glaser R, Crespin T & Carson III WE (2007). Distress reduction from a psychological intervention contributes to improved health for cancer patients. *Brain, Behavior, and Immunity*, 21: 953-961.
63. Danhauer SC, Rutherford CA, Hurt G, Gentry S, Lovato J & McQuellon RP (2007). Providing psychosocial group support for young women with breast cancer: Findings from a wellness-based community collaboration. *Journal of Psychosocial Oncology*, 25: 103-120.

64. Dirksen SR & Epstein DR (2007) Efficacy of insomnia intervention on fatigue, mood and quality of life in breast cancer survivors. *Journal of Advanced Nursing*, 61: 664-675.
65. Kissane DW, Grabsch B, Clarke DM, Smith GC, Love AW, Bloch S, Snyder RD & Li Y (2007). Supportive-expressive group therapy for women with metastatic breast cancer: Survival and psychosocial outcome from a randomised controlled trial. *Psycho-Oncology*, 16: 277-286.
66. Zimmerman T, Heinrichs N & Baucom DH (2007). "Does one size fit all?" moderators in psychosocial interventions for breast cancer patients: A meta-analysis. *Annals of Behavioural Medicine*, 34: 225-239.
67. Classen CC, Kraemer HC, Blasey C, Giese-Davis J, Koopman C, Gronskaya Palesh O, Atkinson A, DiMicelli S, Stonisch-Riggs G, Westendorp J, Morrow GR & Spiegel D (2007). Supportive-expressive group therapy for primary breast cancer patients: A randomised prospective multicenter trial. *Psycho-Oncology*, 17: 438-447
68. Stefanek ME, Jacobsen PB & Christensen AJ (2006). The society of behavioural Medicine's "Great Debate": An introduction. *Annals of Behavioral Medicine*, 32: 83-84.
69. Coyne JC, Lepore SJ & Palmer SC (2006). Efficacy of psychosocial interventions in cancer care: Evidence is weaker than it first looks. *Annals of Behavioral Medicine*, 32: 104-110.
70. Nezu A, Nezu C, Felgoise S, McClure K, Houts P (2003). Project Genesis: Assessing the efficacy of problem solving therapy for distressed adult cancer patients. *Journal of Consulting and Clinical Psychology*, 71: 1036-1048.
71. Andersen BL, Farrar WB, Golden-Kreutz DM, Glaser R, Emery CF, Cressin TR, Shapiro CL & Carson WE III (2004). Psychological, behavioral, and immune changes after a psychological intervention: A clinical trial. *Journal of Clinical Oncology*, 22: 3570-3580.
72. Scott J, Halford K & Ward B (2004). United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. *Journal of Consulting and Clinical Psychology*, 72: 1122-1135.
73. Boesen EH, Ross L, Frederiksen K, Thomsen BL, Dahlstrom K, Schmidt G, Naested J, Krag C & Johansen C (2005). Psychoeducational intervention for patients with cutaneous malignant melanoma: A replication study. *Journal of Clinical Oncology*, 23: 1270-1277.
74. Manne SL & Andrykowski MA (2006). Are psychological interventions effective and accepted by cancer patients? II. Using empirically supported therapy guidelines to decide. *Annals of Behavioral Medicine*, 23: 98-103.
75. Ross L, Boesen EH, Dalton SO & Johansen C (2002). Mind and cancer: Does psychosocial intervention improve survival and psychological well-being? *European Journal of Cancer*, 38: 1447-1457.
76. Barsevick AM, Sweeney C, Haney E, Chung E (2002). A systematic qualitative analysis of psycho-educational interventions for depression in patients with cancer. *Oncology Nursing Forum*, 29: 73-87.
77. Groot de MH. (1991). Psychometrische aspecten van een stemmingschaal (verkorte POMS). *Gedrag en Gezondheid*, 20: 46-51.
78. Hosaka T, Aoki T, Watanabe T & Ishida A (1994). Psychiatric evaluation of rehabilitation patients. *Tokai Experimental Clinical Medicine*, 1-2: 7-11.
79. Rhoades, HM, Grabowski J, Elk R & Cowan K (1993). Factor stationary and invariance of the POMS in cocaine patients. *Psychopharmacological Bulletin*, 29: 263-267.
80. Folkman S (1997). Positive psychological stress and coping with severe stress. *Social Science and Medicine*, 45: 1207-1221.
81. Sprangers MAG, Groenvold M, Arraras JI, Franklin J, te Velde A, Muller M, Franzini L, Williams A, de Haes HCJM, Hopwood P, Cull A & Aaronson NK (1996). The EORTC Breast Cancer-Specific Quality of Life Module (QLQ-BR32): First results from a three-country field study. *Journal of Clinical Oncology*, 14: 2756-2768.
82. Osoba D, Aaronson N, Zee B, Sprangers M & te Velde A (1997). Modification of the EORTC QLQ-C30 (version 2.0) based on content validity and reliability testing in large samples of patients with cancer. *Quality of Life Research*, 6: 103-108.

A Appendix

Analyzing the difference between
psycho-therapy groups and social support
groups for breast cancer patients:
The use of video recordings

Bert Garssen

Petra J. Vos

Eltica de Jager Meezenbroek

Cora de Klerk

Adriaan P. Visser

Abstract

When comparing the efficacy of different interventions for cancer patients, there should be certainty that these types are sufficiently different in the way they are actually presented. The focus of the present study is on the difference between support groups and experiential-existential psychotherapy groups. Independent and blind raters assessed video fragments of both intervention types, using a self-developed checklist. This checklist was first evaluated by a group of experts for appropriateness, importance, and reliability. Three out of the five questions were selected on the basis of these experts' evaluation and on inter rater reliability. The scores on these questions were used to evaluate five social support groups and six experiential-existential psychotherapy groups for breast cancer patients. According to the independent and blind raters the content of the two intervention forms appeared to be significantly different. It is concluded that this method of assessment, is profitably as a check to compare the aimed content of psycho-oncological interventions.

Introduction

The effectiveness of psychological interventions for people with cancer has been demonstrated in many controlled and randomized studies [1-10]. Although most of these studies did find an improvement with respect to anxiety, depression, worry, confusion, self-esteem, experienced control, quality of relationships and somatic symptoms, there is limited knowledge about which types of psycho-oncological interventions make a significant contribution to their effectiveness.

Various group interventions have been compared [11-16]. The types of group interventions distinguished in these studies are: Self-help groups [17,18], social support groups with and without psycho-education [15], cognitive behavioral oriented 'stress management'/coping skills training' groups [19-22], psychodynamic therapy groups [23], and experiential-existential centred therapy groups [24]. The contrast most often studied, is between support groups and stress management groups [11-14]. Stress management appeared to be more efficacious than social support alone. Helgeson et al. (2000) [15] compared group psycho-education, peer-discussion (support group) and no therapy. Psycho-education -either on its own or in combination- generated greater benefits than supportive discussions alone.

Differences between social support and experiential-existential psychotherapy groups

We compared the effectiveness of social support groups and experiential-existential psychotherapy groups; a contrast which had not been evaluated before. The present study is part of an intervention project [25].

When comparing different intervention types, there should be certainty that these forms are sufficiently different in the way they are presented during the study. The distinctive features of social support and experiential-existential psychotherapy groups are rather subtle (see Table 1), which makes such a check the more necessary.

Table 1: Similarities and differences in goals between social support groups and experiential-existential psychotherapy groups

	Social support group	Therapy group
1. Group leader has a professional background in psychotherapy	not necessary	necessary
2. Mutual support group members	yes	yes
3. Exchange of disease and treatment related experiences and emotions	yes	yes
4. Discussion of practical solutions for disease and treatment related problems	always	regularly
5. Psycho-education	always	often
6. Utilizing group processes for learning	rarely	always
7. Attention for personal meaning of experiences and emotions	rarely	always
8. Systematically analysing problems	rarely	always
9. Encouragement to express emotions	may occur	always

Sivesind and Baile [26] mentioned four distinctive features of social support groups. (1) Support groups offer in their view concrete guidelines, such as directing patients as to when they should report troubling symptoms to their physician, which is often discouraged in psychotherapy groups. The difference is, in our view, more gradual. A therapy group for cancer patients will not avoid discussion of practical aspects, although explicit guidelines do indeed tend to be set more often in a support group. (2) According to Sivesind and Baile (1997), support groups often run for an indefinite period of time and change members frequently, whereas psychotherapy groups usually have an identified ending point and strive to maintain a stable group membership. Support groups are in our view indeed more often open-ended, whereas therapy groups are more often closed and time limited. However, these differences are far from being absolute and not imperative. (3) Members of support groups are often identified by a common problem, whereas in group psychotherapy, members are not, according to Sivesind and Baile (1997). However this characteristic does not always apply. If it means limiting group membership to a certain disease, phase of disease or subgroup, then this limitation has been applied in psychotherapeutical interventions, focused on specific groups, such as spouses of lung cancer patients [27], adolescents with cancer [28], metastatic breast cancer patients [29,30] or gastrointestinal patients undergoing surgery [31]. (4) According to Sivesind and Baile [26], group psychotherapy generally focuses on making personal changes through insight to enhance interpersonal skills or relieve intrapsychic distress. Support groups, in contrast, specialize in helping patients cope with the trauma of an illness, such as cancer or another life crisis, decreasing the sense of isolation of group members and helping find a new meaning in life. However, the delineated aims for support groups apply in our view equally to therapy groups. It would be unfortunate if therapy groups for cancer patients did not have these objectives.

Common and important elements in both interventions are in our view: Mutual support among group members and sharing experiences and emotions. Social support groups are more practically oriented and tend to dedicate more attention to psycho-education (conceived as structured provision of information about the disease, its treatment and psychological adjustment, and discussion of this information). In psychotherapy groups, psychotherapists will use the group interaction as learning experiences for participants. They also systematically analyse psychological problems of participants and focus on the personal meaning of the experiences and emotions expressed by participants, more than leaders of social support groups do. Emotional expression itself is important in psychotherapy, partly because venting one's emotions can be salutary in itself, but mainly because it helps to discover what is essential to the individual. Emotional activation is often a clue to what is personally relevant. These differences are related to the professional background of group leaders, which is often a psychotherapist in therapy groups, whereas leaders of support groups are more often social workers, medical doctors or oncology nurses (without extensive psychotherapeutic training).

Aim of the study

The aim of the present study is to analyze the differences between social support groups and experiential-existential psychotherapy groups in the way they are offered to patients. A checklist was developed on the basis of the abovementioned differences; to be used by independent raters to score recorded video fragments of both intervention types. The relevance and validity of the checklist was first evaluated by a group of experts. Subsequently, the checklist was applied by independent raters, who rated the video fragments of group therapy and social support group sessions to determine inter rater reliability. On the basis of the experts' opinions and the inter rater reliability scores, questions were selected that appeared to be valid, relevant and reliable for analyzing the differences between support groups and experiential-existential psychotherapy groups. Based on the selected questions it was established whether the two intervention forms actually differed in the expected direction. Further, the degree to which an intervention group fulfils the psychotherapy and social support group model, was determined for each of the eleven groups that participated in this study.

Methods

Design of the study

This study is part of a larger intervention study to evaluate the effectiveness of psychotherapy groups in comparison to social support groups. Breast cancer patients were randomly allocated to a psychotherapy, social support or waiting list condition. Patients in the waiting-list condition were later randomly allocated to one of the two types of intervention [25]. The sample included six therapy and five social support groups. Each intervention consisted of twelve weekly sessions and two follow-up sessions, which were scheduled one and two months after the last weekly session. Sessions lasted two-and-a-half hours and included a short break halfway through.

For the purpose of this study every second, sixth and eleventh session was recorded on video. Afterwards, five minutes fragments were selected from each session: One before and one after the break. Fragments had to satisfy the following two conditions to be included in the evaluation tape. First, it should not include a meditation or relaxation exercise, and secondly it should show at least two people speaking, one of whom was a therapist/group leader. The first fragment, which after twenty minutes of the videotape satisfied the two mentioned conditions, was chosen. Video fragments were selected from the eleven groups, three sessions per group, and two fragments from each session, making a total of 66 fragments minus three unusable fragments, due to failed recordings. The selected 63 fragments were placed in random order on a new tape and were rated by three raters, who were blinded to the conditions.

The raters were three paid psychology students, who had completed a short observation training course. During this training course they practised the rating system, using recordings from group sessions made during a pilot study. The raters were intentionally not provided with descriptions of a psychotherapy group and social support group. The raters were blinded to the type of intervention. They were expected to use their own expertise as clinical psychology students in answering this question.

The checklist

The checklist consisted originally of five questions, presented in Table 2. The questions in the checklist are based on the differences between a social support group and an experiential-existential therapy group, as described in Table 2. Question 1 is mainly related to point 4 and 5 in Table 1. Question 2 refers to point 3, 4 and 8 in Table 1, while question 3 refers to points 3 and 4, and question 4 to point 3, 4, and 6.

The descriptions of the two intervention types were intentionally labelled with the neutral description of an A and B type of intervention, and not as descriptions of a therapy group and a social support group, to prevent any possible prejudices by the raters. The first four questions included a short description of a 'Type A' and a 'Type B' intervention. The raters

Table 2: The checklist for scoring social support groups and experiential- existential therapy groups

Answering categories for question 1 - 4: 'The fragment, you just saw, shows agreement with the description of ... intervention A / intervention B / somewhat of both interventions / no agreement with either type'

Question 1

Type A: 'The group supervisors have a guiding role, though attention is also given to themes introduced by the participants. Participants are provided with a lot of information about the disease and its treatment, psychological reactions, and practical adjustments.'

Type B: 'The group supervisors stimulate and guard the group process: Does everyone receive sufficient attention, are individual differences honoured, and is sufficient attention paid to the personal meaning of experiences?'

Question 2

Type A: 'Emotional aspects are discussed, but the emphasis is on practical solutions to the problems discussed.'

Type B: 'Practical solutions are discussed, but the emphasis is on emotional aspects and personal meaning of problems and solutions.'

Question 3

Type A: 'If participants have found solutions to their problems themselves, they are invited to share them. That people are themselves often capable of finding their own solutions is emphasized, and attention is also paid to what people are good at, in addition to those problems they are struggling with.'

Type B: 'If participants have found solutions to their problems themselves, they are invited to share them, because these solutions may be helpful to others.'

Question 4

Type A: 'Discussing certain topics may touch participants emotionally. Room for expressing emotions is allowed for, but this is not the focal point. Finding a practical solution is attempted.'

Type B: 'Discussing certain topics may touch participants emotionally. Time to express emotions is allowed for and what these emotions mean to the individual is discussed.'

Question 5

Does the fragment represent mainly a 'therapy group', 'a social support group', both or neither of both

were asked to score whether a fragment was 'more Type A', was 'more Type B', 'somewhat of both Type A and Type B', or was 'neither similar to Type A or Type B'. For questions 1, 2 and 4 the answer 'resembling more Type A' was coded as -1; 'more Type B' was coded as +1; and 'somewhat of both Type A and type B' or 'neither Type A or Type B' was coded as 0. For question 3 the coding was the opposite. The fifth question asked directly whether the rater found the fragment mainly representing 'a psychotherapy group', 'a social support group', 'somewhat of both', or 'neither of both' (later coded as 1, -1, 0 and 0, respectively).

Evaluation of the checklist

We asked twelve experts in the field of psycho-oncology to evaluate the relevance and appropriateness of the first four questions in the checklist, supposing; there was no doubt about the relevance and appropriateness of the fifth question. Eight psychotherapists and four support group leaders were asked to indicate on a checklist, first, which of the two descriptions for each question they would classify as describing a social support group; secondly, whether they thought the descriptions were appropriate; in the third place whether the descriptions expressed an important difference between the two types of intervention; and fourth whether they thought the question could be reliably rated.

Statistical procedure

Kappa coefficients were used to determine inter rater reliability. A squared weighted Kappa coefficient was used to value a difference of one point between two raters as more acceptable than a difference of 2. A difference of 1 point occurs, for instance, if one rater defines a fragment as 'Type A', while the other rater defines the fragment as 'neither of both'. A difference of 2 points is obtained if one rater defines a fragment as 'Type A', whereas the other defines it as 'Type B'. A Kappa larger than 0.40 is considered as reasonable [32].

To determine whether the raters were able to differentiate between the two intervention forms on the basis of the video fragments, only those questions were used that were rated as acceptable by the experts and showed sufficient inter rater reliability. The raters' scores for the two intervention types were compared with a General Linear Model Repeated Measures Procedure, using the mean of the scores of the three raters. In this analysis, the 'cases' are the eleven groups (six versus five cases). Each 'case' has six repeated measures (= the scores for the six video fragments per group, averaged for the three raters). The repeated measurements in this study are interrelated at two levels: The three sessions of each group are interrelated and the two fragments of each session are interrelated, nested within the first series of data. A significance level of $p=.05$ was used in all tests.

Results

Evaluation of the checklist

The experts rated three of the four questions (1, 2 and 4) as appropriate, important and rateable: Their mean scores were between 2 ('reasonably') and 3 ('good').

When asked which description (A or B) referred to a social support group or psychotherapy group, one of the twelve experts systematically scored in a direction opposite to what we considered correct on theoretical grounds. All other experts agreed on questions 2, 3 and 4. However, question 1 was only by 8 of the 12 experts scored in the "correct" direction. On the basis of these expert ratings only questions 2 and 4 appeared to be valid and relevant (see Table 3).

Table 3: Evaluation of the checklist by the twelve experts. Mean values of appropriateness, importance and rateability of the questions are presented. Scores range from 0 ('not at all') to 4 ('very').

	Question 1	Question 2	Question 3	Question 4
Appropriate	2.6	2.8	1.8	2.3
Important	2.8	2.8	2.1	3
Rateable	2.9	3.0	1.5	2.6

Inter rater reliability

The squared weighted Kappa coefficients of the five questions are presented in Table 4.

Question 1 and 3 could be considered as unreliable, because the inter rater reliability is too low. Question 2 as nearly reliably and question 4 as rated reasonably reliably, according to the view of Landis and Koch (1977) [32].

Table 4: Reliability of the questions.

	Squared weighted Kappa coefficient
Question 1	0.15
Question 2	0.38
Question 3	0.17
Question 4	0.44
Question 5	0.47

A check was made to determine whether one of the raters systematically deviated in his judgement from the other two raters, which appeared not to be the case. A check was also made to determine whether reliability was different for fragments before or after the interval, or differed per session. This was generally not the case, with some rare exceptions (reliability was sometimes lower for session 2, compared to the later sessions for questions 2 and 4).

The difference between the two intervention types

For this analysis only question 2 and 4 were used, because only these questions appeared to be valid and relevant. The raters' scores did not change over time. There was no significant effect for session (early, middle or late session) or interval (before or after interval). Only once was an interaction effect noted: for question 2 the interaction between session, interval and intervention type was significant ($p=.03$ for a Multivariate Test).

What is most important, is that the main effect for intervention type was significant for the three remaining questions (question 2, $F=11.4$, $p=.008$; question 4, $F=13.9$, $p=.005$; question 5, $F=23.6$, $p=.001$). Apparently, the raters rated the two intervention types as being different. Table 5 and 6 show the mean scores for psychotherapy and social support groups, for the different type of fragments: Early, middle or late session (Table 5) and before or after the interval (Table 6).

Table 5: Mean raters' scores per session and intervention type.

	Therapy groups (n=5)			Social support groups (n=6)		
	Session 2	Session 6	Session 11	Session 2	Session 6	Session 11
Question 2	0.49	0.31	0.11	-0.26	-0.63	-0.07
Question 4	0.33	0.33	0.00	-0.33	-0.50	-0.33
Question 5	0.39	0.33	0.06	-0.52	-0.67	-0.67

Positive score = more like a psychotherapy group; negative score = more like a social support group

Table 6: Mean raters' scores for fragments before and after the interval per intervention type.

	Therapy groups (n=5)		Social support groups (n=6)	
	Before interval	After interval	Before interval	After interval
Question 2	0.17	0.43	-0.38	-0.29
Question 4	0.15	0.29	-0.60	-0.19
Question 5	0.19	0.33	-0.79	-0.45

Positive score = more like a psychotherapy group; negative score = more like a social support group

As expected, psychotherapy group fragments were rated as psychotherapeutic (scores > 0) and social support group fragments were in general rated as social supportive (scores < 0). The scores for the therapy groups were near zero during the last session, which means that they are then judged as being in between a psychotherapy and social support type of intervention. Intervention types differ the most in week six (the middle session) and fragments after the interval are more therapy alike than before the interval.

Though it was demonstrated that psychotherapy groups were rated by independent and blind raters as being different from social support groups, some psychotherapy groups could have been in fact more like a social support group and vice versa. Figure 1-3 show the mean scores (average of the six scores for each fragment) for the eleven groups with respect to the three most important questions.

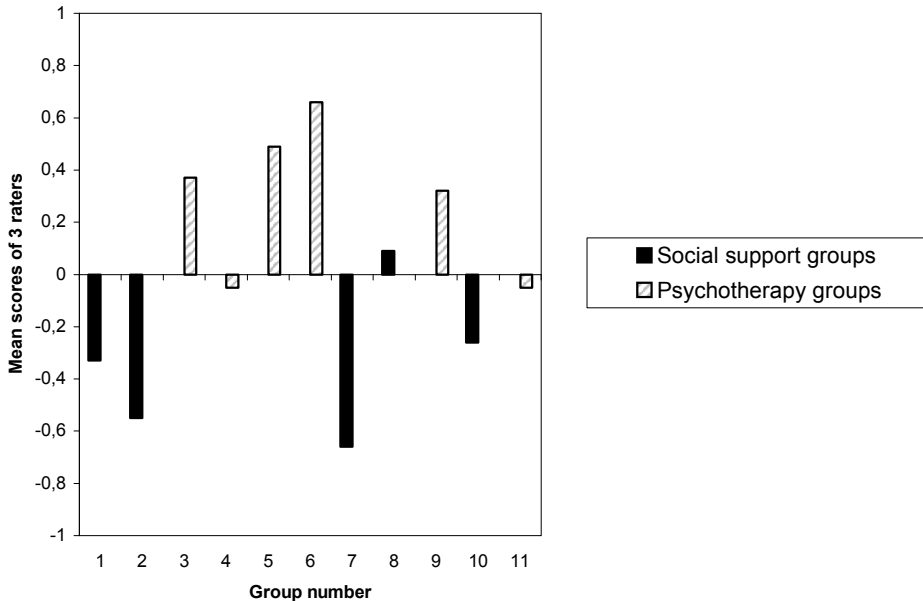


Figure 1: Mean scores to question 2 for each of the eleven groups

The figures show that there is quite some difference in how the groups were rated. Some groups were rated as not clearly representing the expected intervention type, or even as representing the not-intended type of intervention (Group 4, 5, 8 and 11).

Discussion and conclusion

The aim of the present study is to analyze the differences between social support groups and experiential-existential psychotherapy groups in the way they are presented to the clients. Therefore a checklist was developed, based on theoretical grounds to distinguish their manifestations of both interventions in practice. These two types, namely a social support group condition and an experiential-existential psychotherapy group, differ only gradually, which makes a test for actual differences even more important. Further it is necessary that the differences should appear from observable behavior of group members and group leaders and be determinable by raters who have interest in but are not specialised in this specific field of psycho-oncological interventions. Another difficulty was the absence of generally accepted guidelines in the literature about what constitutes a support group and a psychotherapy group.

A checklist with five questions was developed, to be used by three independent raters in their assessment of video fragments of therapy and social support groups. A group of experts evaluated the appropriateness, importance and rateability of the first four questions. Two

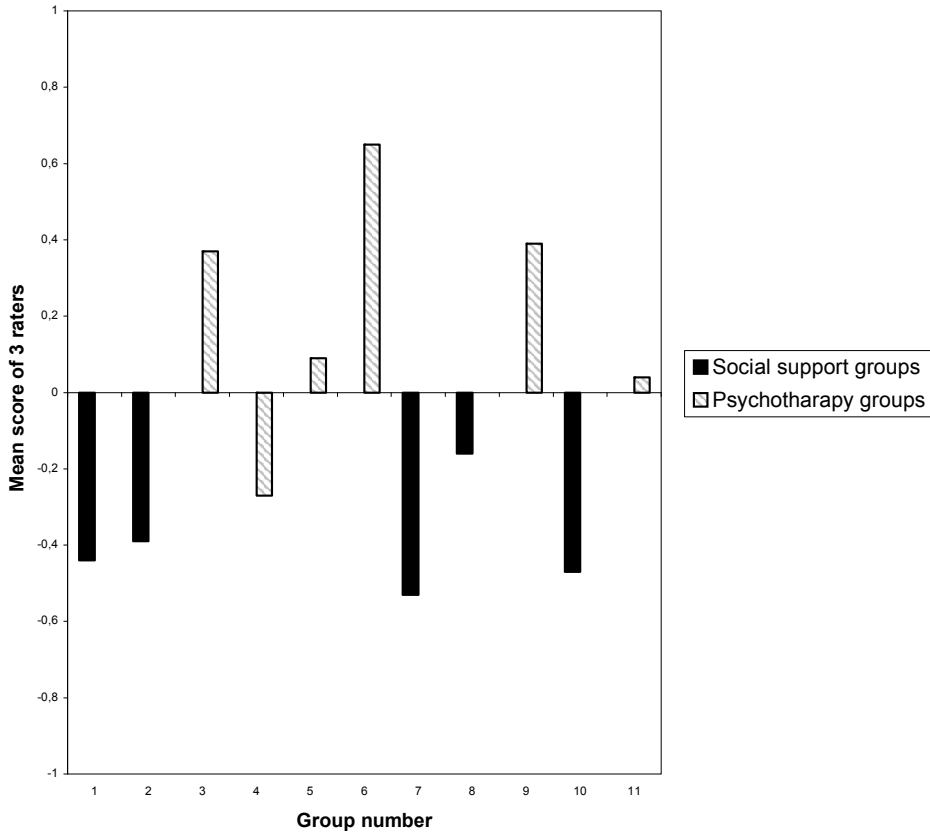


Figure 2: Mean scores to question 4 for each of the eleven groups

questions were rejected on the basis of their evaluation. Three independent raters scored the video fragments using the five questions and agreed on most questions except two based at the Kappa coefficients. These were the same two questions already rejected by the group of experts.

The three main questions were used to determine whether the two intervention forms differed, according to the independent raters, in the direction that was theoretically assumed. Despite the low power of this test, being based on six repeated measurements for only six intervention groups versus five social support groups, all three tests showed a significant difference. The scores for all three questions were in the expected direction. Apparently, the raters found the content of the two types of intervention clearly different.

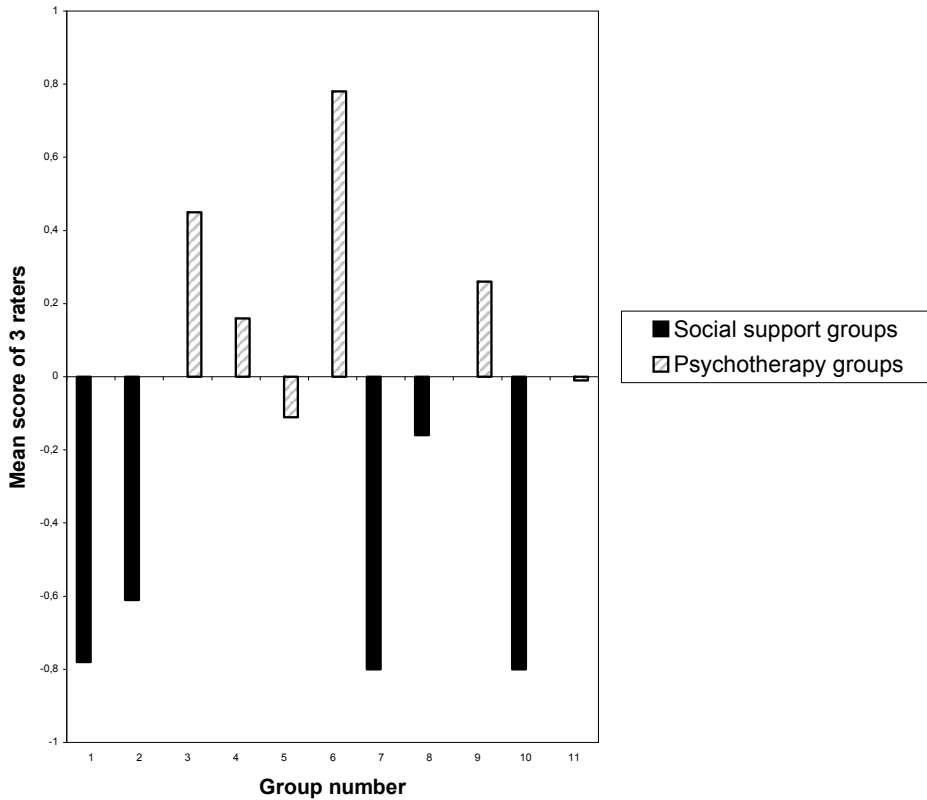


Figure 3: Mean scores to question 5 for each of the eleven groups

Discussion

It is a methodological flaw to test validity and reliability of a measuring method in a certain sample, and to use the same sample to apply this method for testing a hypothesis. However, the samples for testing validity, reliability and intervention differences were different. Three tests were performed in this study. First a test on relevance and rateability of the checklist, Second a test of inter rater reliability, and in the third place a test whether the two intervention forms differed in their actual manifestations. The samples for these three tests consisted of the group of experts, the three judges, and the eleven intervention groups, respectively. The items of the checklist were chosen on the basis of expertise of therapists at our institute and our own view as therapy researchers, because generally accepted guidelines for social support groups and therapy groups for people with cancer and formulations about their differences, did not exist. There is a lack of uniformity in the classification of these types of intervention. A clear description of what constitutes a support group and a therapy group is difficult to pinpoint from the literature [33-35]. Our conception of a social support group is comparable to the 'support group therapy' and 'supportive counseling' condition applied by

Telch and Telch (1986) [11] and Moorey et al. (1998) [36] respectively, which they compared to a cognitive behavioral intervention. These investigators used the support group condition to control for the attention and support given by the therapist in the coping skills training condition. In our case the effects of support groups and psychotherapy groups were compared.

Conclusion

A concomitant advantage of an assessment method, as developed in the present study, is the necessity to conscientiously analyse and formulate the differences between support groups and therapy groups. Types of interventions and their distinctive characteristics have not been clearly described in the psycho-oncological literature and, consequently, intervention studies cannot be easily compared.

References

1. Trijsburg RW, van Knippenberg FC & Rijkma SE (1992). Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine*, 54: 489-517.
2. Andersen BL (1992). Psychological interventions for cancer patients to enhance the quality of life. *Journal of Consulting and Clinical Psychology*, 60: 552-568.
3. Meyer TJ & Mark MM (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychology*, 14: 101-108.
4. Fawzy FI, Fawzy NW, Arndt LA & Pasnau RO (1995). Critical review of psychosocial interventions in cancer care. *Archives of General Psychiatry*, 52: 100-113.
5. Helgeson VS & Cohen S (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15: 135-148.
6. Fobair P (1997). Cancer support groups and group therapies .1. Historical and theoretical background and research on effectiveness. *Journal of Psychosocial Oncology*, 15: 63-81.
7. Fobair P (1997). Cancer support groups and group therapies: Part II. Process, organizational, leadership, and patient issues. *Journal of Psychosocial Oncology*, 15: 123-147.
8. Fawzy FI, Fawzy NW & Canada AL (1998). Psychosocial treatment of cancer: An update. *Current Opinions in Psychiatry*, 11: 601-605.
9. Edelman S, Craig A & Kidman AD (2000). Group interventions with cancer patients: Efficacy of psychoeducational versus supportive groups. *Journal of Psychosocial Oncology*, 18: 67-85.
10. Owen JE, Klapow JC, Hicken B & Tucker DC (2001). Psychosocial interventions for cancer: Review and analysis using a three-tiered outcomes model. *Psycho-Oncology*, 10: 218-230.
11. Telch CF & Telch MJ (1986). Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. *Journal of Consulting and Clinical Psychology*, 54: 802-808.
12. Cunningham AJ & Tocco EK (1989). A randomized trial of group psychoeducational therapy for cancer patients. *Patient Education and Counseling*, 14: 101-114.
13. Evans RL & Connis RT (1995). Comparison of brief group therapies for depressed cancer patients receiving radiation treatment. *Public Health Reports*, 110: 306-311.
14. Edelman S, Bell DR & Kidman AD (1999). Group CBT versus supportive therapy with patients who have primary breast cancer. *Journal of Cognitive Psychotherapy*, 13: 189-202.
15. Helgeson VS, Cohen S, Schulz R & Yasko J (2000). Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology*, 19: 107-114.
16. Edgar L, Rosberger Z & Collet JP (2001). Lessons learned: Outcomes and methodology of a coping skills intervention trial comparing individual and group formats for patients with cancer. *International Journal of Psychiatry in Medicine*, 31: 289-304.
17. Hitch PJ, Fielding RG & Llewelyn SP (1994). Effectiveness of Self-Help and Support Groups for Cancer Patients - A Review. *Psychology & Health*, 9: 437-448.
18. Gray RE & Fitch M (2001). Cancer self-help groups are here to stay: Issues and challenges for health professionals. *Journal of Palliative Care*, 17: 53-58.
19. Fawzy FI, Cousins N, Fawzy NW, Kemeny ME, Elashoff R & Morton D (1990). A structured psychiatric intervention for cancer patients. I. Changes over time in methods of coping and affective disturbance. *Archives of General Psychiatry*, 47: 720-725.
20. Greer S, Moorey S, Baruch JD, Watson M, Robertson BM, Mason A, Rowden L, Law MG & Bliss JM (1992). Adjuvant psychological therapy for patients with cancer: A prospective randomised trial. *British Medical Journal*, 304: 675-680.
21. Moorey S, Greer S, Watson M, Baruch JD, Robertson BM, Mason A, Rowden L, Tunmore R, Law M & Bliss JM (1994). Adjuvant psychological therapy for patients with cancer: Outcome at one year. *Psycho-Oncology*, 3: 39-46.
22. Fawzy FI, Fawzy NW & Hyun CS (1994). Short-term psychiatric intervention for patients with malignant melanoma: Effects on psychological state, coping and the immune system. In Lewis C.E., O'Sullivan C. & Barraclough J. (Eds) *The psychoimmunology of cancer. Mind and body in the fight for survival*, Oxford Medical Publ., Oxford, 291-319.
23. Kaufman E & Micha VG (1987). A model for psychotherapy with the good-prognosis cancer patient. Conducted at a time when the patient is amenable to change. *Psychosomatics*, 28: 540-548.

24. Spiegel D, Bloom JR & Yalom I (1981). Group support for patients with metastatic cancer. A randomized prospective outcome study. *Archives of General Psychiatry*, 38: 527-533.
25. Vos PJ, Visser AP, Garssen B, Duivenvoorden HJ & de Haes HCJM (2007). Effectiveness of group psychotherapy compared to social support groups in patients with primary, non-metastatic breast cancer. *Journal of Psychosocial Oncology*, 25: 37-60.
26. Sivesind DM & Baile WF (1997). An ovarian cancer support group. *Cancer Practice*, 5: 247-251.
27. Goldberg RJ & Wool MS (1985). Psychotherapy for the spouses of lung cancer patients: Assessment of an intervention. *Psychotherapy and Psychosomatics*, 43-44: 141-150.
28. Baider L & De-Nour AK (1989). Group therapy with adolescent cancer patients. *Journal of Adolescence and Health Care*, 10: 35-38.
29. Leszcz M & Goodwin PJ (1998). The rationale and foundations of group psychotherapy for women with metastatic breast cancer. *International Journal of Group Psychotherapy*, 48: 245-273.
30. Edelman S, Bell DR & Kidman AD (1999). A group cognitive behavior therapy programme with metastatic breast cancer patients. *Psycho-Oncology*, 8: 295-305.
31. Kuchler T, Henne-Bruns D, Rappat S, Graul J, Holst K, Williams JI & Wood-Dauphinee S (1999). Impact of psychotherapeutic support on gastrointestinal cancer patients undergoing surgery: Survival results of a trial. *Hepatogastroenterology*, 46: 322-335.
32. Landis J & Koch GC (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33: 159-174.
33. Krupnick JL, Rowland JH, Goldberg RL & Daniel UV (1993). Professionally-led support groups for cancer patients: An intervention in search of a model. *International Journal of Psychiatry in Medicine*, 23: 275-294.
34. Spiegel D (1994). Health caring. Psychosocial support for patients with cancer. *Cancer*, 74: 1453-1457.
35. Cunningham AJ & Edmonds CVI (1996). Group psychological therapy for cancer patients: A point of view, and discussion of the hierarchy of options. *International Journal of Psychiatry in Medicine*, 26: 51-82.
36. Moorey S, Greer S, Bliss J & Law M (1998). A comparison of adjuvant psychological therapy and supportive counseling in patients with cancer. *Psycho-Oncology*, 7: 218-228.

Nederlandse samenvatting

In de laatste decennia van de vorige eeuw is de kennis met betrekking tot de medische behandeling van kanker sterk toegenomen. Chemotherapie en hormonale therapie werden geïntroduceerd en voor verschillende vormen van kanker werden screeningprogramma's opgezet om kanker in een vroeg stadium te kunnen ontdekken. Eén van de gevolgen van deze vooruitgang op het medische gebied is dat vrouwen met borstkanker een grotere overlevingskans hebben, vooral als de borstkanker in een vroeg stadium ontdekt wordt. Dit betekent echter ook, dat zij langer geconfronteerd worden met de nadelige gevolgen zoals een aangetast lichaam als gevolg van de borstoperatie of zelfs borstamputatie, vermoeidheid als gevolg van chemotherapie, en psychosociale gevolgen zoals angst, depressie, seksuele problemen en sociale problemen.

Om deze psychosociale gevolgen te minimaliseren, zijn over de hele wereld patiëntspecifieke interventieprogramma's ontwikkeld. Bij aanvang van deze studie, in 1995, toonde de meerderheid van deze onderzoeken aan dat psychosociale begeleiding emotionele stress verminderde en het omgaan met de psychosociale gevolgen van kanker verbeterde. Resultaten lieten zien dat psychosociale interventies een aanvulling vormden op de medische behandeling van kanker.

Onduidelijk bleef echter welke elementen uit de interventies verantwoordelijk waren voor de verbeteringen. Om dit na te gaan is het huidige onderzoek opgezet, waarin twee soorten van begeleiding met elkaar werden vergeleken:

1. groepstherapie gebaseerd op experiëntiële-existentiële uitgangspunten
2. sociale steungroep.

Beide interventies duurde 12 weken en werden aangeboden aan vrouwen die een diagnose borstkanker hadden gekregen en hier 3 weken tot 4 maanden geleden aan geopereerd waren. Allen hadden een goede prognose, wat wil zeggen dat er geen uitzaaiingen op afstand waren gevonden.

Er was sprake van een gerandomiseerd onderzoek, waarin de vrouwen dus niet de keus hadden aan welke vorm van begeleiding zij deelnamen. Daarnaast startte de helft van de begeleiding meteen na toewijzing aan één van beide interventies (dus groepstherapie of sociale steungroep), terwijl de andere helft van de interventies pas 3 maanden na de toewijzing startte (wachtlIJstgroep). Ook dit gedeelte was gerandomiseerd.

De hypothese was dat de deelnemende vrouwen een verbetering op het psychosociale gebied zouden laten zien, maar dat deze verbetering beduidend groter zou zijn bij de groep vrouwen die deelgenomen hadden aan de groepstherapie. Daarnaast was de gedachte dat de vrouwen die meteen met de begeleiding gestart waren direct na afloop een verbetering op psychosociaal gebied zouden laten zien, terwijl de vrouwen die op dat moment nog moesten starten met hun begeleiding geen vooruitgang of zelfs een achteruitgang op psychosociaal gebied zouden rapporteren. Dit proefschrift beschrijft de resultaten van dit onderzoek.

Het aanbieden van psychosociale begeleiding kort na de diagnose borstkanker en de daaropvolgende operatie is gebaseerd op de aanname dat vrouwen op dat moment de meeste psychosociale problemen ervaren. Dat deze veronderstelling gerechtvaardigd is, blijkt uit de resultaten van verschillende onderzoeken die aangeven dat tot 56% van vrouwen met een diagnose borstkanker aangeven emotionele problemen te hebben. Bij de meeste vrouwen worden deze problemen veel minder of verdwijnen ze. Toch heeft na 1 jaar ongeveer 1/3 van de vrouwen nog psychosociale problemen.

In **hoofdstuk 2** wordt beschreven in hoeverre de deelnemers aan dit onderzoek psychosociale problemen hadden en of er een relatie is tussen de verschillende soorten psychosociale problemen aan de ene kant (emotionele stress, vitaliteit, seksueel functioneren, lichaamsbeeld, recreatieve activiteiten en sociale interacties) en medische en demografische gegevens, sociale steun en de manier van omgaan met problemen aan de andere kant.

Uit dit onderzoek bleek dat de vrouwen die aan deze studie deelnamen weinig psychosociale problemen hadden. Ze waren vergelijkbaar met vrouwen die geen borstkanker hadden. Daarnaast werd gevonden dat vlak na de diagnose en operatie met name het op een ziektespecifieke manier omgaan met de diagnose borstkanker en de gevolgen ervan gerelateerd was aan eventueel psychosociale problemen. Hoe men over het algemeen omgaat met problemen was minder relevant.

Vrouwen die aangaven op een optimistische manier met hun ziekte om te gaan, rapporteerden minder emotionele stress, meer vitaliteit, een beter lichaamsbeeld, participeerden meer in recreatieve activiteiten en werden minder belemmerd in hun sociale interacties. Vrouwen die met hun ziekte omgingen door er heel erg op gericht te zijn, gaven juist meer emotionele stress aan en hadden een negatiever lichaamsbeeld. Vrouwen die de gedachte aan hun ziekte onderdrukte, ervoeren meer emotionele stress en minder vitaliteit.

Daarnaast bleek dat oudere vrouwen en vrouwen die een borstbesparende operatie hadden ondergaan vaker op een optimistischer manier met hun ziekte omgingen. De laatste groep vrouwen had ook een positiever lichaamsbeeld dan vrouwen met een borstamputatie.

In dit deel van het onderzoek kon de positieve rol van sociale steun, die in ander onderzoek vaak gevonden wordt, niet bevestigd worden.

De volgende stap in het onderzoek was de groep vrouwen die meteen na de randomisatie met de begeleiding begonnen waren te vergelijken met de vrouwen die 3 maanden op de wachtlijst stonden en bijna zouden beginnen met hun begeleiding. De resultaten van deze vergelijking zijn beschreven in **hoofdstuk 3**. Op het moment dat de vrouwen aangaven deel te willen nemen aan dit onderzoek en zij nog niet wisten in welke groep ze zouden komen en wanneer de groep zou starten, is er geen verschil tussen de vrouwen die meteen met de begeleiding zijn begonnen en de vrouwen die op de wachtlijst terecht kwamen. Dit gold

voor medische en demografische gegevens, psychosociale problemen, sociale steun en de manier van omgaan met problemen.

Aan het eind van dit deel van het onderzoek bleek er opnieuw geen verschil te zijn tussen de vrouwen die de begeleiding juist hadden afgerond en de vrouwen die op de wachtlijst stonden en bijna zouden starten met de begeleiding als het ging om psychosociale problemen en het omgaan met problemen. Wel bleken de vrouwen die deelgenomen hadden aan de sociale steungroep meer steun van onbekenden te ervaren in vergelijking met vrouwen die aan de therapiegroep hadden deelgenomen en de vrouwen die nog aan de begeleiding moesten beginnen.

Een ander resultaat was dat de vrouwen die deel hadden genomen aan de begeleiding niet veranderd waren op psychosociaal gebied na deelname aan de begeleiding. De conclusie van dit deel van het onderzoek is dat vrouwen gediagnosticeerd met borstkanker, maar zonder psychosociale problemen, geen baat hebben bij een kortdurende begeleiding op de korte termijn in vergelijking met vrouwen die (nog) geen begeleiding hebben ontvangen.

In **hoofdstuk 4** wordt het effect van snel starten of pas na 3 maanden wachtlijst starten met de begeleiding beschreven. De helft van de vrouwen die hadden toegezegd mee te willen werken aan dit onderzoek, werd voor 3 maanden op een wachtlijst geplaatst. De vergelijking tussen de deelnemers die meteen na het starten van het onderzoek en de deelnemers die 3 maanden op een wachtlijst stonden is gedaan voor aanvang van de begeleiding, meteen nadat de begeleiding afgelopen was en een half jaar nadat de begeleiding afgerond was.

De belangrijkste uitkomst van dit deel van het onderzoek was dat de vrouwen die eerst 3 maanden op de wachtlijst stonden, zes maanden nadat de begeleiding afgelopen was, meer emotionele stress rapporteerden dan de vrouwen die meteen gestart waren met de begeleiding. Hieruit zou geconcludeerd kunnen worden dat vrouwen bij wie borstkanker gediagnosticeerd is en die hiervoor geopereerd zijn, zo snel mogelijk na deze operatie psychosociale begeleiding zouden moeten krijgen.

In dit deel van het onderzoek is ook gekeken of er een verschil op psychosociaal gebied was vlak nadat de begeleiding was afgerond en een half jaar daarna ten opzichte van voor de begeleiding. Net als in hoofdstuk 3, werd ook nu vlak nadat de begeleiding afgelopen was geen verschil op psychosociaal gebied gevonden ten opzichte van vlak voor de begeleiding. Zes maanden nadat de begeleiding was afgerond, werd er echter wel een verandering gerapporteerd: vrouwen gaven aan een verbeterd lichaamsbeeld te hebben en ook meer deel te nemen aan recreatieve activiteiten. Daarnaast was er een neiging tot een positieve verandering in de mate van emotionele stress en werden er minder sociale interacties ervaren. Deze veranderingen konden echter niet toegeschreven worden aan deelname aan één van beide vormen van begeleiding, maar waren het gevolg van het verstrijken van de tijd.

Het belangrijkste doel van dit onderzoek was om de effecten van de sociale steungroepen te vergelijken met de effecten van experiëntiële-existentiële groepstherapie. Dit wordt in **hoofdstuk 5** beschreven. De hypothese was dat de deelnemers aan beide vormen van begeleiding een verbetering op het psychosociaal gebied zouden rapporteren, waarbij de verbetering van de vrouwen die deelgenomen hadden aan de groepstherapie beduidend groter zou zijn dan de verbetering door deelname aan de sociale steungroep. De beide groepen zijn vergeleken voor aanvang van de begeleiding, meteen nadat de begeleiding was afgerond en 12 maanden daarna.

Zoals in voorgaande hoofdstukken werd er ook nu geen verschil gevonden tussen de beide vormen van begeleiding, op geen van de tijdstippen waarop vergeleken werd. En ook nu werd er over het algemeen, los van de begeleiding waar men aan deelgenomen had, geen verbetering op enig psychosociaal gebied gevonden vlak nadat de begeleiding afgelopen was. Wel werd er 12 maanden nadat de begeleiding afgerond was een verbetering van het lichaamsbeeld en een vermeerdering van deelname aan recreatieve activiteiten gerapporteerd. Het in hoofdstuk vier gevonden verschil op 6 maanden, bleek ook na 12 maanden nog aanwezig te zijn. Echter, ook nu kon de verandering alleen toegeschreven worden aan het verstrijken van de tijd en niet aan deelname aan een van beide vormen van begeleiding.

In **hoofdstuk 6** wordt de rol van het op een ziektespecifieke manier van omgaan met het hebben (gehad) van borstkanker onderzocht. Er werd alleen ingegaan op de ziektespecifieke manier van omgaan, omdat eerder al (hoofdstuk 2) was gebleken dat deze manier van omgaan met de ziekte van grotere invloed is op het psychosociaal welbevinden dan hoe men over het algemeen met problemen omgaat.

Allereerst is de stabiliteit van zowel psychosociaal welbevinden als het omgaan met problemen op een ziektespecifieke manier onderzocht. Het bleek dat beiden redelijk stabiel waren door de tijd heen: het psychosociaal welbevinden dat de deelnemers aan het begin aangaven te hebben, was aan het eind van de studie (15 tot 18 maanden later) niet veranderd. Dit gold ook voor de manier van omgaan met de ziekte.

Verder werd gevonden dat vrouwen die een optimistische houding hadden als manier van omgaan met hun ziekte een positiever sociaal welbevinden ervoeren. Vrouwen die echter een ziekte gerichte manier van omgaan met problemen aangaven, rapporteerden een minder psychosociaal welbevinden. Tenslotte gaven vrouwen die de gedachte aan hun ziekte onderdrukten aan dat zij bij de start van de studie minder vitaliteit ervoeren. Met het verlopen van de tijd, bleek deze relatie niet meer te bestaan

De algemene conclusie van dit onderzoek is dat deelname aan een sociale steungroep of een experiëntiële-existentiële groepstherapie niet effectief is voor de vermindering van psychosociale problemen bij vrouwen met een diagnose borstkanker die daarvoor kort geleden geopereerd zijn en een goede prognose hebben. De twee vormen van begeleiding

lieten tevens geen verandering in het omgaan met problemen zien en ook werd er over het algemeen niet meer sociale steun ervaren door deelname aan één van beide groepen. Het enige resultaat was dat het lichaamsbeeld van de deelnemende vrouwen over het algemeen verbeterde en dat zij aan het eind van de studie aangaven meer aan recreatieve activiteiten deel te nemen ten opzichte van het begin van de studie. Deze positieve veranderingen waren echter niet het effect van deelname aan één van beide groepsbegeleidingen, maar waarschijnlijk het resultaat van het verstrijken van de tijd.

Het gevonden resultaat is teleurstellend als uitgegaan wordt van de kennis die in 1995 voorhanden was. Als dit onderzoek echter vergeleken wordt met onderzoek dat in de afgelopen 5 jaar gepubliceerd is, waarin vergelijkbare vormen van interventies vergeleken worden, blijkt dat de resultaten overeen komen. Bovendien is er vanaf 2002 kritischer ingegaan op het interventie onderzoek en de conclusie van sommige onderzoekers luidt dat de gerapporteerde onderzoeken een te rooskleurig beeld van de werkelijkheid geven. Toch betekent dit niet dat vrouwen met een borstkanker diagnose geen begeleiding nodig zouden hebben. De vrouwen die aan dit onderzoek meewerkten, waardeerden de begeleiding wel degelijk. De deelnemers aan de sociale steungroep gaven een gemiddeld cijfer van 8,0 en de deelnemers aan de psychotherapiegroep van 7,9. Daarnaast gaven zij aan de kwaliteit van de begeleiding goed tot zeer goed te vinden, indien nodig nog een keer aan een dergelijke zelfde soort begeleiding deel te willen nemen en deze begeleiding aan andere vrouwen in dezelfde situatie aan te raden.

Op basis van het resultaat van dit onderzoek lijkt het niet nodig alle vrouwen die gediagnosticeerd worden met borstkanker standaard psychosociale begeleiding aan te bieden. Voor de meeste vrouwen is het voldoende dat zij weten dat er een mogelijkheid is begeleiding te krijgen, waar deze begeleiding te krijgen is en vooral dat deze begeleiding laagdrempelig is. Dit betekent echter niet dat er geen taak meer is voor het ziekenhuis waar de diagnose gesteld wordt. Binnen het ziekenhuis zouden alle vrouwen gescreend moeten worden op de aanwezigheid van en het risico voor het ontwikkelen van psychosociale problemen. Deze groep vrouwen zou op een meer actieve wijze psychosociale begeleiding aangeboden moeten krijgen.

Bij vergelijking van twee verschillende vormen van interventies, is het noodzakelijk dat deze interventies daadwerkelijk van elkaar verschillen. In de **appendix** wordt de methode om het verschil tussen de sociale steungroepen en de therapiegroepen van elkaar te onderscheiden beschreven. Daarnaast wordt beschreven of de uitgevoerde interventies ook daadwerkelijk van elkaar verschilden.

Van alle groepen (zes therapiegroepen en vijf sociale steungroepen) zijn in de tweede, zesde en elfde bijeenkomst video-opnames gemaakt. Uit deze video-opnames zijn per groep en per opgenomen bijeenkomst twee fragmenten gekozen die ad random op een videoband gezet werden. De fragmenten die gekozen werden, moesten aan een aantal voorwaarden

voldoen: ze mochten geen meditatie of relaxatie oefening bevatten en er moest interactie tussen tenminste twee personen zijn, waaronder de groepsleider of de therapeut. Het eerste fragment dat 20 minuten na aanvang van de bijeenkomst en na de pauze aan deze voorwaarde voldeed, werd gekozen.

De fragmenten werden beoordeeld door een drietal psychologiestudenten die geen binding met het onderzoek hadden en ook niet wisten om welke vormen van begeleiding het ging. De beoordeling van de fragmenten ging aan de hand van een aantal vragen. Experts hadden de gebruikte vragen beoordeeld op betrouwbaarheid, importantie en toepasbaarheid.

Het resultaat van het beoordelen van de videofragmenten was de interventies (sociale steungroepen en therapiegroepen) voldoende van elkaar verschilden om met elkaar vergeleken te kunnen worden. Een andere conclusie was dat de beschreven methode voldoet om het verschil tussen twee soorten interventies aan te tonen.

Dankwoord

Na bijna 13 jaar is het zover dat dit proefschrift afgerond is. Een proefschrift dat niet zonder de hulp van een aantal mensen tot stand had kunnen komen. Allereerst de medewerking van alle vrouwen. Vlak nadat jullie geopereerd waren omdat er borstkanker was geconstateerd, werd er gevraagd of jullie deel wilden nemen aan een begeleiding die 3 maanden zou duren. En jullie zeiden ja. Bedankt voor jullie aanwezigheid in de groepen, voor de koffie en koek die ik en de andere interviewers kregen als we langskwamen bij jullie thuis. Ik hoop dat jullie het goed maken.

Geachte prof. dr. De Haes, beste Hanneke, zonder jou zou dit proefschrift nooit afgemaakt zijn. Wij zagen elkaar soms zeer lange tijd niet en misschien heb je je regelmatig afgevraagd of deze promotie er ooit zou komen. Toch heb je mij altijd het gevoel weten te geven op de goede weg te zijn. Onze gesprekken, met name die van het afgelopen jaar, waren voor mij heel inspirerend en stimulerend. Dank voor je vertrouwen en wijze en praktische commentaren.

Geachte dr. Visser, beste Adriaan, als begeleider hebben wij zeer veel gesprekken over dit onderzoek gehad. Met name voor wat betreft de praktische kanten waren we het vaak met elkaar eens. In het uitvoeren van dit onderzoek heb ik een grote mate van vrijheid ervaren, waardoor het echt 'mijn' onderzoek is geworden. Dank daarvoor en voor de vele adviezen die je me gaf.

Geachte dr. Garssen, beste Bert, als tweede begeleider van het onderzoek hebben ook wij vele gesprekken gevoerd. De inhoud van deze gesprekken was vaak theoretisch van aard. Ik heb er veel van geleerd. En gemerkt dat als iemands stijl niet de jouwe is, er toch veel goeds in kan zitten. Dank voor je vaak zeer weloverwogen commentaar op mijn manuscripten, daardoor zijn zij zeker beter geworden.

Zonder de hulp van specialisten en mamma- en oncologieverpleegkundigen in de ziekenhuizen zou dit onderzoek niet van start hebben kunnen gaan. Dokter Meijer (MCRZ-locatie Clara), dokter Tetteroo, Melanie van Logchem, Renske Koper (IJsselland Ziekenhuis), zuster Boelhouwer (Vlietland Ziekenhuis, locatie Schiedam), dokter van Dam, Coby Klap, Anja Sparrenboom (Haven Ziekenhuis), dokter Bannink (Erasmus MC – Daniel den Hoed), dokter van Eijk (Erasmus MC), dokter Bleker, dokter van Beek (Ruwaard van Putten Ziekenhuis) en Janny Salomé (St. Franciscus Gasthuis) dank voor jullie medewerking en het doorsturen van vrouwen voor deelname aan dit onderzoek.

Het Integraal Kankercentrum Rotterdam (IKR) heeft gedurende de periode dat de groepen 'liepen' altijd een zaal kosteloos beschikbaar gesteld voor de sociale steungroepen. Dank voor deze gastvrijheid.

Zonder begeleiders geen groepen. Petra Korlaar, Ria de Vries, Annelies Boeken Kruger-van Dijk, Heleen Jonker-Elfferich, jullie hebben de sociale steungroepen vol verve geleid. Gezien de reacties die ik terug kreeg in het interview na 1 jaar, hebben jullie dat heel goed gedaan. Dank voor jullie inzet en betrokkenheid.

Zonder Trudy v.d. Jagt (IKR) geen groepsbegeleiders. Dank dat je de groepsbegeleiders hebt getraind en aanwezig was als zij vragen hadden.

Maar ook zonder therapeuten geen groepen. Beste Edel Maex, Judit Brommer, Welmet Hudig, Hank Malinowski, Frans Meulmeester, Gerda Barkmeijer, Klazien de Vries-Kragt (†), Rita Schockaert, Paul Hoekstra en Hanneke Hoekstra-Oving voor jullie was het niet altijd gemakkelijk. De therapie die jullie al jaren gaven moesten jullie ineens via een protocol gaan geven en aan groepen die anders van samenstelling waren dan jullie gewend waren. Regelmatig hebben jullie je twijfels daarover geuit. Door jullie zijn het 'mooie' groepen geworden. Dank voor jullie aandacht en professionaliteit.

De vrouwen die meegedaan hebben aan dit onderzoek moesten twee keer geïnterviewd worden. Dat kon ik niet allemaal alleen doen. Beste Ella, Christine, Lisa, Margot, Angelique, Barbara, Valeska, Petra, Marije, Isabella, Connie, Ursula, Elsa, Annalisa, René, Sandra en Babette, dank voor het uitvoeren en uitwerken van deze interviews.

Zonder statistiek, geen mooie resultaten. Beste Hugo, op onnavolgbare wijze heb je me de in en outs van SEM laten zien, me geleerd dat je soms beter RRM kunt gebruiken dan AN(C)OVA's. Iedere keer als ik (na een lange tijd) weer met een statistische vraag bij je kwam, pakte je het weer op alsof ik gisteren nog langs geweest was. Dank daarvoor.

Zonder de steun van collega's kan een proefschrift niet tot stand komen. Lieve Aly, de laatste jaren hebben we niet veel contact meer. Echter, bij het HDI was jij mijn steun en toeverlaat. In woorden is bijna niet uit te drukken hoezeer ik je waardeer. Beste Cora, de taak van Aly overnemen was bijna onmogelijk. Toch is het je gelukt om dat op je eigen manier te doen. Dank, zonder jullie steun zou mijn tijd bij het HDI lang zo leuk niet zijn geweest. Beste Cock en Ria, jullie hebben mij geleerd hoe belangrijk een secretariaat is. Dank voor de vele praatjes en de koffie. Beste Ursula, Patty, Jeffrey, Roelinda, Dirk, Pieta, Ria en Margot Z, dank voor alle gezelligheid.

Maar ook de collega's van nu zijn belangrijk. Beste IKR-ers, dank voor jullie belangstelling. Lieve Mathilde, als kamergenoot ben je onvervangbaar. Dank voor het aanhoren van mijn stress en het mee willen lezen als ik je daarom vroeg.

Lieve Margot, jij was vanaf de basis betrokken bij dit onderzoek. Zonder jou zou het onderzoek nooit geweest zijn wat het nu geworden is. Je inzicht, gezelligheid en vooral steun is onbetaalbaar.

Lieve Silvia, ooit samen begonnen als voetbalvrouw van het 9^e van Excelsior M (Wat is de stand? Geen idee!), ben je uitgegroeid tot mijn beste vriendin. Ik heb veel van je geleerd en bewonder je om je kracht. Jouw vriendschap is van onschatbare waarde voor me.

Lieve Margot en Silvia, ik ben er trots op dat jullie vandaag naast me willen staan.

En dan thuis. Kinderen krijgen tijdens een promotietraject is niet handig. Lieve Kristel, Tamar en Norah, mede door jullie komst heeft het zo lang geduurd voordat dit boekje er was. Maar ik zou me er niet druk om maken als ik jullie was. Jullie zijn het wachten waard!

Lieve Ron, het is gelukt. Tussen al jouw marathontrainingen, kinderactiviteiten en werk is er toch nog tijd gevonden om dit proefschrift af te ronden. Met name het afgelopen jaar heb jij je aangepast door je trainingen op zondag aan mij aan te passen en de rust te bewaren als ik

door de stress voor de 100^{ste} keer mijn brood vergat. Dank je wel dat je, met name de laatste maanden steeds weer mijn buien weerstond en steeds weer naar me luisterde als ik het even niet zag zitten. In het komende Sinterklaas gedicht mag je de promotie nog 1 keer noemen: het is afgerond!

Curriculum Vitae

Petronella Jeanine (Petra) Vos is op 21 december 1966 geboren in Maassluis. Na het behalen van haar VWO diploma aan het Interconfessioneel Westland College te Naaldwijk is zij gaan werken als medewerkster particuliere relaties bij de ABN Bank. In 1989 is zij begonnen met de studie Psychologie aan de Rijksuniversiteit Leiden. In 1993 heeft zij deze studie afgerond met een onderzoek naar coping en kwaliteit van leven bij mensen die een hart- of herseninfarct hadden gehad.

Na haar studie is zij één jaar werkzaam geweest als onderzoeker bij de afdeling Medische Psychologie en Psychotherapie van de Erasmus Universiteit Rotterdam, waar zij een onderzoeksvoorstel geschreven heeft naar medicijngebruik onder (huis)artsen. In 1994 is zij (onbezoldigd) gaan werken bij de afdeling Medische Psychologie van de Vrije Universiteit Amsterdam. Hier heeft zij meegeschreven aan een onderzoeksvoorstel met betrekking tot medisch onverklaarbare lage rugpijn.

Vanaf december 1995 tot 2002 is zij werkzaam geweest bij het Helen Dowling Instituut te Rotterdam (vanaf 2001 te Utrecht) als Onderzoeker in Opleiding. Het onderzoek van dit proefschrift is in deze periode uitgevoerd.

In oktober 2001 heeft zij de overstap naar het Integraal Kankercentrum Rotterdam (IKR) gemaakt. In eerste instantie als projectbegeleider binnen de oncologische zorg. Hier heeft zij aan verschillende projecten, waaronder Herstel en Balans en Regiovisie Oncologische zorg, meegewerkt. Sinds september 2006 is zij bij het IKR werkzaam als coördinator Palliatieve zorg. Eén van haar belangrijkste taken binnen de afdeling Palliatieve zorg, is de begeleiding van diverse instellingen en organisaties bij de implementatie van het Zorgpad Stervensfase.

Petra Vos is getrouwd en heeft 3 dochters.