Group Rehabilitation for Cancer Patients:

Effects, Patient Satisfaction, Utilisation and Prediction of Rehabilitation Need

BY

LENA-MARIE PETERSSON

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ABSTRACT

The aims are to investigate cancer patients' perceived satisfaction with a Group Rehabilitation (GR) intervention, to evaluate its effects, and to explore the extent to which the patient's coping style (monitoring, blunting) modulates the effects of the GR. An additional aim is to investigate to what extent some aspects of health-related quality of life (HRQOL) [Physical Functioning (PF), Emotional Functioning (EF) and Global Quality of Life (QoL)] one year after diagnosis can be predicted on the basis of medical, socio-demographic and psychological data collected at diagnosis. Patients (n=481) newly diagnosed with breast, gastrointestinal or prostate cancer, were randomly assigned (Support-Care-Rehabilitation project) to one of four alternatives: 1. "Individual Support" (IS) starting at diagnosis; 2. "Group Rehabilitation" (GR) starting approximately four months later; 3. A combination of IS and GR; or 4. "Standard Care" (SC). All patients were monitored for two years. The GR comprised eight weekly sessions and one booster session after two months. The 2.5-hour meetings dealt with information about cancer, treatment, nutrition, cognitive behaviour therapy (CBT), light physical training and relaxation. Patients rated the physical and informative components as somewhat more beneficial than the CBT component. Meeting others was also rated as beneficial. However, there were limited effects on quality of life and anxiety. The monitoring concept was useful for distinguishing a subgroup of cancer patients (prostate cancer monitors) who benefited from the GR programme. Regression analyses demonstrated that the presence of advanced disease at diagnosis predicted a reduced physical function one year later. Having one or more comorbid conditions predicted lower PF and QoL. EF was predicted only by lower mental well-being and being classified as a case on the basis of the HADS. Indications for offering rehabilitative programs to cancer patients are critically discussed.

Keyword: Cancer, group rehabilitation, patient satisfaction, coping style, prediction

Lena-Marie Petersson, Uppsala University, Department of Public Health and Caring Sciences, Section for Caring Sciences, Uppsala Science Park, SE-751 83 Uppsala, Sweden

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Byta ett ord eller två
gjorde det lätt att gå.
Alla människors möte
borde vara så.

Hjalmar Gullberg
ORIGINAL PUBLICATIONS

This doctoral thesis consists of the present summary and the following papers, which are referred to by their Roman numerals.


* shared first authorship

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<td>AA</td>
<td>Availability of Attachment</td>
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<td>ANCOVA</td>
<td>Analyses of covariance</td>
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<td>APT</td>
<td>Adjuvant Psychological Therapy</td>
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<td>Availability of Social Integration</td>
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<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<td>EF</td>
<td>Emotional Function</td>
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<td>EORTC QLQ-C30</td>
<td>European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C-30</td>
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<tr>
<td>GI</td>
<td>Gastrointestinal cancer (here colorectal or gastric cancer)</td>
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<td>GR</td>
<td>Group Rehabilitation</td>
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<td>GQLI</td>
<td>Göteborg Quality of Life Instrument</td>
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<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
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<td>HRQOL</td>
<td>Health Related Quality of Life</td>
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<td>IES</td>
<td>Impact of Event Scale</td>
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<td>ISSI</td>
<td>Interview Schedule for Social Interaction</td>
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<td>InQ</td>
<td>Inclusion Questionnaire</td>
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<td>IPHC</td>
<td>Intensified Primary Health Care</td>
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<td>IPS</td>
<td>Individual Psychological Support</td>
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<td>IS</td>
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<td>ISGR</td>
<td>Individual Support and Group Rehabilitation</td>
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<td>KPS</td>
<td>Karnofsky Performance Status</td>
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<td>LSD</td>
<td>Least Significant Difference</td>
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<td>MBSS</td>
<td>Miller Behavioural Style Scale</td>
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<td>NS</td>
<td>Nutritional Support</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<td>PF</td>
<td>Physical Function</td>
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<td>SC</td>
<td>Standard Care</td>
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<td>SCR</td>
<td>The Support-Care-Rehabilitation-project</td>
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<tr>
<td>SPCG-IV</td>
<td>Scandinavian Prostate Cancer Group Study IV (patients with localised disease, i.e. T 1-2, N 0, M 0, randomised between prostatectomy vs. expectance)</td>
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Cancer

Every year, more than 40,000 persons are diagnosed with cancer in Sweden, and the life-time risk to develop cancer is above one third. About two thirds of persons diagnosed with cancer are older than 65 years (National Board of Health and Welfare, 1999). Cancer is not one disease, but rather a group of more than 200 diseases, the natural history and treatment of which are dictated by the particular cancer site and type. The treatment of choice for most cancer types is surgery, with the aim to remove the entire tumour. Additional treatments, generally chemotherapy, radiotherapy and/or hormonal treatment, are sometimes given in order to improve the outcome. These treatments are also used as curative treatments for some cancer types. Presently, more than 50% of cancer patients can be “cured” from their disease. The improvements seen through the years are partly due to better treatments, generally being more intensive than they were in the past. Even if not cured, many persons with cancer, e.g. of the breast and prostate, may live and function well for many years. Cancer can thus be regarded as a chronic disease for many persons. Rehabilitation is potentially important for patients with cancer, whether cure is achieved or one or several recurrences occur, as they must learn how to live with a cancer diagnosis. Rehabilitative interventions are performed with the intention to facilitate cancer patients’ achievement of full physical, psychological, social, vocational, avocational and educational potentials within the limits imposed by the disease and treatment (Kurtzman et al., 1988).

The context of the present thesis is that patients with breast, colorectal, gastric, or prostate cancer were offered participation in a Support-Care-Rehabilitation (SCR) project. The SCR project will be described below. These diagnoses were chosen since they are common and represent diseases with different treatments and prognoses.
**Breast cancer**

Breast cancer is the most common type of cancer among women (National Board of Health and Welfare, 1999). Approximately 5,800 new cases are reported every year in Sweden. In Uppsala county, the corresponding figure is 160 new cases. The risk for developing breast cancer increases with age, and the disease is uncommon before the age of 30. The median age at diagnosis is 65 years (National Board of Health and Welfare, 1999). The five-year relative survival varies between 90 and 100 % for those with the best prognosis, and between 20 and 40 % for those with more advanced disease.

The main treatment of breast cancer is surgery, and the majority of patients are treated with breast conserving surgery (sector resection). Mastectomy is performed if the tumour is large or locally advanced. Preoperative chemotherapy alone or with radiotherapy may be needed to reduce the tumour before surgery in locally advanced cases. In order to plan the treatment, axillary lymph nodes are investigated. Postoperative radiation therapy is given to most women during about five weeks to diminish the risk of locoregional recurrence. Women with a definite risk for recurrence are recommended systemic adjuvant therapy. This may include chemotherapy, hormonal therapy (antiestrogen) or a combination of these. The intensity of the treatments varies considerably between patients in different prognostic groups.

**Colorectal cancer**

Approximately 5,000 new cases of cancer of the colon and rectum are reported every year in Sweden (National Board of Health and Welfare, 1999). In Uppsala county, about 130 new cases are reported yearly. Two third of the tumours are located in the colon and one third in the rectum.
The survival of patients with colorectal cancer has improved during past decades. This is partly due to reduced postoperative mortality but also to better treatments, particularly for rectal cancer (Dahlberg et al., 1998; Glimelius et al., 2001). It is possible to expect even better prognosis due to better diagnostic possibilities, screening, and additional treatments. The disease is equally common in men and in women. Colorectal cancer is rare before the age of 55 and only about 35 % of the cases are diagnosed before the age of 70. The median age at diagnosis is about 74 years.

The prognosis for colorectal cancer is closely related to the stage of the disease. The five-year survival according to the commonly used Dukes’ classification system is 90-100 % for stage A, 60-80 % for stage B, 35-55 % for stage C and < 5 % for stage D. Untreated patients, diagnosed with a Dukes D tumour has an expected median time of survival of less than 6 months.

The primary treatment for colorectal cancer is surgery. Pre-operative radiotherapy is frequently given to rectal cancer patients in order to minimise the risk for local recurrence (Glimelius & Isacsson, 2001). Between 10 and 15 % of all rectal cancers are inoperable at diagnosis. These are treated preoperatively with radiotherapy and/or chemotherapy. Some patients receive adjuvant chemotherapy after surgery. Chemotherapy and/or radiotherapy are also given as palliative treatments in order to reduce symptoms, prolong life, and enhance quality of life for patients with incurable disease.

Gastric cancer

About 1,300 new cases of gastric cancer are diagnosed every year in Sweden (National Board of Health and Welfare, 1999). In Uppsala county, about 30 new cases are reported yearly.
Gastric cancer occurs about twice as often in men as in women. The mean age at diagnosis is 73 years for men and 77 years for women.

The symptoms of gastric cancer are often uncharacteristic and are in the early stages similar to those for benign disease (i.e. ulcer). The prognosis is poor since the cancer is often diagnosed in an advanced stage. Only about 20 % of all gastric cancer patients are alive after five years. The treatment of gastric cancer is surgery. Additional treatments are generally not given, although the results of recent trials may change this (Macdonald et al., 2001). As for colorectal cancer patients, palliative chemotherapy and/or radiotherapy may prolong life, reduce symptoms and enhance quality of life. Sometimes, palliative surgery is performed in order to alleviate problems with swallowing, pain, vomiting and bleeding.

Prostate cancer

Prostate cancer is the most common cancer among Swedish men (National Board of Health and Welfare, 1999). Every year, almost 7,000 new cases are reported. In Uppsala county, about 200 new cases are reported yearly. Prostate cancer is rare before the age of 55 and about 75 % of the afflicted patients are 70 years or older. The prognosis of clinically localised prostate cancer is often very good. The five-year survival ranges from about 65 to 90 %. At diagnosis, about half of the cases have metastases. There is presently no consensus regarding the treatment of choice for patients with localised tumours, since available treatments appear to be equally effective. One alternative is prostatectomy, and another is curative radiotherapy as a combination of internal and external radiotherapy. Since prostate cancers often grow slowly, a third alternative is watchful waiting until symptoms develop. During the course of the SCR-project, a randomised trial (SPCG IV) was performed, comparing watchful waiting with surgery for men with localised disease. The results of this trial have recently shown that
radical prostatectomy significantly reduces disease-specific mortality. However, there was no significant difference in terms of overall survival between surgery and watchful waiting (Holmberg et al., 2002). On average, the choice of watchful waiting or radical prostatectomy had little, if any, influence on well-being or the subjective quality of life after a mean follow-up of four years (Steineck et al., 2002). It might be that watchful waiting should be reserved for older men or men with less than a 10-year life expectancy. For advanced prostate cancer, hormonal therapy is the treatment of choice. This can be done either surgically by castration or medically. When the tumour has become refractory to hormones, it is generally unresponsive to most therapies, although chemotherapy may relieve symptoms. Skeletal metastases are treated by palliative radiotherapy.

Cancer-related problems

The problems that occur in relation to the cancer disease and its treatment vary with the type of cancer, disease stage and type of medical treatment. Difficulties may develop in the period between diagnosis and primary treatment, during primary treatment, and during follow-up. Surgery, chemotherapy and radiotherapy may result in several types of difficulties. Besides physical symptoms and problems, the patient’s psychological and social situation may be severely affected by the disease and treatment. In addition, existential problems may appear in patients facing a potentially severe disease and problematic treatments.

A number of patients with cancer need rehabilitative support from the time of their diagnosis through various treatments for long-term cure – or until death. They may pass through repeated periods of side effects from various treatments. Besides physical and social effects, the emotional burden may be substantial for some patients. Needs for information and support may change throughout the cancer experience. An important trend in cancer treatment is an
increasing emphasis on the overall outcome, not just on survival or the disease-free interval, but also on the functional status and the quality of life of the survivor (Mellette, 1993).

**Cancer rehabilitation**

In the late 1970s and early 1980s, cancer rehabilitation was discussed within the classic context of specific physical deficits due to the disease and its treatment (e.g. amputations and lymphoedema). However, as cancer patients live now longer, research on cancer rehabilitation has come to consider any aspect of the patient’s quality of life that is affected by the disease or treatment (e.g. activities of daily living, psychological, social, sexual functioning) (Blesch, 1996). The emphasis begun to shift from physical rehabilitation to psychosocial concerns in the 1980s, as more attention was paid to support groups, symptom control and palliative care (Mellette, 1993).

Watson (1990) has suggested a global definition of cancer rehabilitation: "Cancer rehabilitation is a dynamic, health-oriented process designed to promote maximum levels of functioning in individuals with cancer-related health problems” (p.4). This definition allows for the application of cancer rehabilitation to individuals with major cancer health problems as well as to those with lesser health concerns. Mellette (1993) describes cancer rehabilitation as the process by which people are enabled to live as fully and effectively as possible within the limitations imposed by the disease or its treatment. It addresses the psychosocial and vocational components of individuals’ lives as well as physical factors. The key concept is that of function - physical, emotional, social, and vocational.

The return to everyday life after disease and treatment implies different tasks depending on the medical context (disease, stage, treatment), and the personal meaning of cancer for the
patient as influenced by the sociocultural context. In addition, individual psychological functioning (personality, coping style, history, age, life cycle goals), and the social context (family situation, social network, social support, possibilities for re-entering work and other social activities) play important roles here (Rowland, 1989).

van Harten et al. (1998) have found that 26% (39/147) of cancer patients (breast, bowel or non-Hodgkin lymphoma) expressed a need for rehabilitation within one to four years after diagnosis. Based on in-depth interviews, suggestions for the content of a pilot programme for cancer patients were: fitness/sports activities, relaxation exercises, patient education (especially disease-related aspects), instruction and counselling on coping strategies, socio-cultural therapy to learn to formulate new and realistic goals in life, and dietary advice.

The patient should play an active role in his or her own rehabilitation. Each cancer patient should be taught health-promotive and disease-preventive behaviours (Watson, 1990). This is especially important since patients are in the hospital for shorter periods, and many come for only one day (maybe only some hours) for chemotherapy or radiotherapy. In other words, rehabilitation should start at the time of diagnosis and be continuous.

**Cognitive behavioural therapy**

Cognitive Behavioural Therapy (CBT) has been shown to be an effective and powerful treatment for anxiety and depression among adults in a number of settings. The cognitive-behavioural perspective is based on the postulate that negative mental and physical symptoms are partly a function of maladaptive thinking, and/or behaviours. Thought monitoring, challenging negative automatic thoughts, problem solving, distraction and methods of relaxation are often employed (Beck et al., 1979). During the last decades, several studies of
cancer patients have utilised behavioural interventions such as problem solving, goal setting, and relaxation (Cain et al., 1986; Cunningham & Tocco, 1989; Fawzy et al., 1990; Telch & Telch, 1986). Telch and Telch (1986) and Fawzy et al. (1990) also incorporated cognitive techniques. Thus, developers of cognitive-behavioural interventions often combine several cognitive and behavioural techniques in order to maximise therapeutic effectiveness.

Cognitive-behavioural interventions have been used to e.g. relieve pain related to cancer and its treatment (Spiegel & Bloom, 1983); alleviate aversive reactions to chemotherapy (Lerman et al., 1990); and to improve emotional well-being (Fawzy et al., 1990). Training in problem-solving and coping skills may help the patient when other problems occur. A meta-analysis by Meyer and Mark (1995) showed that cognitive-behavioural interventions were effective in reducing emotional distress and controlling physical symptoms in cancer patients.

Adjuvant Psychological Therapy (APT) is a cognitive behavioural treatment programme developed for cancer patients (Moorey & Greer, 1989). Initially, APT was developed to be conducted with individual patients, and if possible, their spouses or partners. On average six sessions, each lasting about 1 hour, were held. Therapy focuses on the personal meaning of cancer and on the patient’s coping strategies. Therapy is directed at current problems as defined jointly by the patient and the therapist. A randomised trial of APT has demonstrated significant improvements in various measures of psychological distress, e.g. less anxiety and depression (Greer et al., 1992).

Information

According to the Health and Medical Services Act (SFS 1982:763), patients shall be given information about their state of health, the significance of the treatment, various alternative forms of therapy and their effects, and other significant factors associated with the treatment.
This information must be given in a way that the patient can understand it. Further, care and treatment shall as far as possible be planned together with the patients. Information will help patients with cancer to understand and cope with their disease, and to know what treatment options are available and recommended. Also, information may aid patients to participate in treatment decision making (Davison et al., 1995). Patients with cancer often report unmet needs in relation to the health system and information (Glimelius et al., 1995; Sanson-Fisher et al., 2000). However, it is important to remember that the type and amount of information desired may vary from one patient to another. Information is a very common component of rehabilitative interventions (Cunningham & Edmonds, 1996; Spira, 1998).

Patients’ most important sources of information are physicians and nurses (Nair et al., 2000; Sainio et al., 2001). The provision of information has a positive impact on the patient’s participation in his or her care (Glimelius et al., 1995). Many patients come to out-patient clinics for treatments or follow-up visits. The time pressure is high and it is questionable if there is enough time to give information and for patients to ask questions of importance to them.

Teasdale (1993) emphasises that information is a human communication process that depends less on the decoding of semantic information than upon the inferences that individual recipients draw from the context. One consequence of this is that information should be adapted to the characteristics of individual patients. Patient age and education are two characteristics of importance. Older patients report more information seeking from non-medical sources, e.g. newspapers, television and friends than do young patients (Turk-Charles et al., 1997). Cancer patients with a low level of general education ask fewer questions but are equally aware of the disease compared to patients with a higher level of education (Derman &
Serbest, 1993). The most extreme statement of differential effects of information depending upon patient characteristics is summed up in the so-called Monitoring/Blunting-hypothesis which implies that information has differential effects for patients depending on their “cognitive style” (Miller, 1987).

Physical exercise

MacVicar and Winningham (1986) developed and tested an exercise programme among ten volunteer breast cancer chemotherapy patients. Six patients exercised three times per week for 10 weeks and were compared with four non-exercising controls and six healthy, exercising age-matched controls. Positive outcomes were found for the exercising breast cancer patients on both physiological (oxygen intake, heart rate, and symptom frequency) and mood state parameters. Reduced nausea in the breast cancer patients was reported as a serendipitous finding.

Mock et al. (Mock et al., 1994), reported improvements in anxiety, depression, fatigue and nausea among breast cancer women (n=9) who had participated in a 6-month structured programme of walking compared to controls (n=5). It should be noted that the intervention also included a support group, attended every two weeks. The study sample is small and the design does not allow for an evaluation of the benefits of exercise alone. In a later study (Mock et al., 1997), breast cancer patients (n=46) treated with radiation therapy, were randomised to a 7-week walking programme or to a control condition. The walking programme participants reported significant improvements in physical functioning, anxiety, fatigue and sleep compared to the control group.
Courneya and Friedenreich (1999a) reviewed 24 studies published between 1980 and 1997, dealing with physical exercise and quality of life following cancer. Overall, the studies demonstrated that physical exercise had a positive effect on quality of life including physical, functional, psychological, and emotional well-being. A later update (Courneya et al., 2000), including 12 studies published between 1998 and 2000 showed results consistent with the previous review. Most of the 36 studies involved walking or cycle ergometer programs.

However, exercise adherence is a difficult challenge for healthy adults, and may be made even more difficult by a diagnosis of cancer and its treatments (Courneya & Friedenreich, 1999b). Pinto and co-workers (2002) studied the natural progression of exercise participation after cancer treatment among 69 women who had completed treatment for Stage 0-2 breast cancer. These women did not spontaneously become more active the year after their treatment. However, many of them expressed an intention to become more physically active. The benefits of exercise are experienced only with regular participation.

**Relaxation**

A recent meta-analysis of the effectiveness of relaxation found significant positive effects on treatment-related symptoms (e.g. nausea, pain), and emotional adjustment (e.g. depression, anxiety and hostility) (Luebbert et al., 2001). The effects of relaxation were found to be slightly higher on treatment-related symptoms than on emotional adjustment. Luebbert et al. (2001) speculate about possible explanations of the effect of relaxation on anxiety. Since medical cancer treatment may provoke anxiety about something that cannot be influenced, patients may feel helpless, hopeless and anxious. Relaxation affords an active coping strategy for patients and give them a sense of mastery and control over their problems. Relaxation may
also have potential benefits to patients in other areas of life, long after the cancer treatment is completed.

Studies of group rehabilitation for cancer patients

Group interventions for cancer patients were first documented in the late 1970s when clinicians began to report their experiences of conducting groups for patients with terminal illness (e.g. Spiegel & Yalom, 1978; Yalom & Greaves, 1977). When cancer treatments became more effective, more cancer patients survived, or at least became long-time survivors. This led to an increased interest in psychosocial issues and interventions to help patients at all stages of the disease process.

Group therapy offers three unique advantages compared to individual therapy: (1) Social support. Participants can find a comradeship that they may experience nowhere else. In fact, many patients participate in support groups because of the benefits of seeing and talking with others experiencing the same problem (Bauman et al., 1992); (2) The helper-therapy principle. Patients gain benefits from giving and receiving support; (3) Cost-effectiveness. Group therapy makes the limited professional resources available to many patients (Spiegel et al., 1999). Recent studies have shown that the main reason for oncological outpatients not to participate in psychosocial support was sufficient support from the family, friends or doctors (Eakin & Strycker, 2001; Plass & Koch, 2001).

Several studies of group interventions for adult cancer patients have been published since the 1970ies. Some of these are described below. Studies were included provided that they fulfilled the following criteria. The programme should be structured, and led by a trained
facilitator; the focus should be on learning how to live with cancer; and the design should include randomisation between treatment conditions.

Johnson (1982) randomly selected, matched (pre-test score, age and sex), and then randomised 52 patients who had been diagnosed or rediagnosed within the year as having cancer to a structured education programme (“I can cope”) or a control condition. The “I can cope” consists of eight 1.5 h sessions over 4 weeks. A nurse and a multidisciplinary team provided information about cancer, and dealt with coping with daily health problems, communicating with others, liking yourself, living with limits, and helpful resources. At postintervention, the “I can cope” programme was found to have a significant positive effect on the patients’ scores on assessments of anxiety, meaningfulness in life and knowledge about cancer.

Cain et al. (1986) randomised newly diagnosed patients with gynaecologic cancer to structured thematic counselling: individually at patients’ homes or at the hospital (n=21), in a group setting (n=28), or a control condition (n=31). Mean age was 59 years. The eight weekly, 2 h sessions included nature of cancer, causes, treatment, relaxation, diet and exercise, relating to caregivers and family, and goal setting. A social worker conducted the intervention. In the groups, a nurse, a radiologist, and a dietician provided information in three sessions. One week after completion of the counselling, all groups showed improvements in psychosocial adjustment. After six months, the thematic counselling group had adjusted significantly better than the control group concerning anxiety and depression. They also had more knowledge of their illness, better relationships with caregivers, fewer sexual difficulties, and participated in more leisure activities. The individual and group interventions were found to be equally helpful.
Telch and Telch (1986) randomised cancer patients with mixed diagnoses to coping skills instruction (n=13), supportive therapy (n=14), or control (n=14). Mean age was 41 years. The intervention consisted of six weekly, 1.5 h sessions. The coping skills instruction included relaxation and stress management, communication, problem-solving, constructive thinking, emotional management, and activity planning. Groups were led by a psychologist or a social worker. At postintervention, the coping skills group had lower scores for depression, anger, fatigue and higher vigour than the support and control groups. However, both intervention groups were equally satisfied with the treatment received, group content, group process, and group leader.

Cunningham and Tocco (1989) randomised patients with mixed cancer diagnoses to psychoeducational therapy + supportive discussion (n=28) or supportive discussion alone (n=25). Mean age was 48 years. Since all had requested psychological help, the authors considered it unethical to assign patients to a control group. The six weekly, 2 h sessions were conducted by a psychologist. The education included relaxation training, guided imagery, goal setting and general lifestyle management, e.g. diet and exercise. Immediately after the interventions, patients in the psychoeducational group showed greater improvements in anxiety, depression, and total mood disturbance than those in the supportive intervention.

Berglund and co-workers, (Berglund et al., 1994a; Berglund et al., 1994b) randomised patients with mixed cancer diagnoses (mostly breast cancer) to the “Starting Again” (SA) programme (n=98) or a control condition (n=101). Mean age was 53 years. The SA started within 2 months after post-operative treatment and consisted of eleven 2-h sessions over 7 weeks. During the first four weeks, patients met twice, once for physical training and once for information about cancer, treatment crisis reactions, diet and health, and alternative treatments.
During the last three weeks, patients met once a week for coping training. The groups were led by a nurse assisted by a physical trainer, a physician and a psychologist. The SA group improved more than controls at postintervention with respect to depressive symptoms, physical training, physical strength, body avoidance, cognitive effects and appraisal of having received sufficient information. At 6 and 12 month follow-ups, the SA group showed more improvement than controls with respect to information, physical strength, physical training and fighting spirit.

Evans and Connis (1995) randomised depressed lung, bladder, prostate and head-neck cancer patients to cognitive-behavioural treatment (n=27), social support (n=21), or a control condition (n=24). The groups, led by a social worker, consisted of eight weekly, 1 h sessions. Each session of the CBT had a skill training theme aimed to reduce maladaptive anxiety and depression. In the support groups, members generated the discussion topics for each session. Both intervention groups showed less depression, hostility and somatisation at postintervention. At a 6 month follow-up, only the social support group had fewer psychiatric symptoms and reduced maladaptive interpersonal sensitivity and anxiety.

Fawzy et al. (1990) randomised patients treated with surgery only for malignant melanoma to a structured group intervention (n=40) or a control condition (n=40). Mean age was 42 years. The six weekly, 1.5 h sessions emphasised health education, stress management, coping skills and supportive group psychotherapy. The groups consisted of 7-10 participants and were led by a psychiatrist, a lay leader, and a nurse. The intervention group had higher levels of vigour and used more active-behavioural coping methods at post-intervention. This difference had increased in magnitude at the 6 month follow-up. Beneficial effects on survival have been found at 6 (Fawzy et al., 1993) and 10 (Fawzy et al., 2003) year follow-ups. A post-hoc
comparison of the effects of the intervention delivered in individual and group format found them both to be helpful in reducing affective distress up to one year after diagnosis. However, improvement was greater for the group intervention (Fawzy et al., 1996).

One hundred and seven newly diagnosed patients (within 3-6 weeks) with mixed cancer diagnoses were screened and those 31 who were found to be psychologically distressed were offered interventions (Bottomley, 1998; Bottomley et al., 1996). Those who accepted were allocated to group cognitive behavioural therapy (CBT) (n=9) or a social support group (n=8). Those who declined to enter the intervention groups served as controls (n=14). The CBT consisted of a highly structured intervention based on Adjuvant Psychological Therapy (Moorey & Greer, 1989) and consisted of eight weekly, 1.5 h sessions. A psychologist and counsellor conducted the groups. At post-intervention, the CBT group demonstrated significant improvement of scores on anxiety, fighting spirit, and anxious preoccupation. This suggests that they increased their use of coping skills to reduce their anxiety. No differences were found between the groups at a 3 month follow-up. Qualitative analysis from post-intervention interviews showed that both groups experienced positive effects of the intervention. The patients in the CBT group reported that problem-solving and coping techniques were valuable to them.

Edelman et al. (1999a) randomised patients with metastatic breast cancer to a cognitive behavioural therapy (CBT) intervention (n=62) or a control condition (n=62). Mean age was 50 years. The intervention included eight weekly, 2 h sessions, followed by a family night, and 3 monthly sessions. The content was CBT as well as encouraging the expression of feeling and building of group support. The groups were led by two therapists, of which at least one was a psychologist. Significant improvements of quality of life and self-esteem were
found in the CBT group at postintervention. This was not sustained at a 4 month follow-up. The authors pointed out the problem of recruiting patients. During their first 4 years, approximately 200 patients were contacted, and 38 agreed to participate. The most common reason for declining was illness-related. No survival advantage was found after 5 years (Edelman et al., 1999b).

Helgeson et al. (1999) randomised women with breast cancer, shortly after diagnosis, to education (n=79), peer discussion (n=74), a combination of education and peer discussion (n=82) or a control group (=77). Mean age was 48 years. The interventions consisted of eight weekly, 45-60 minute sessions and were led by nurses and social workers together with a physician, a dietician, and a physical therapist. Three monthly booster sessions were held after termination. The education covered breast cancer, adverse effects of chemotherapy, nutrition, exercise, body image, communication, future health care issues, relationships/sexuality and relaxation. The peer group consisted of facilitator-led group discussions with an emphasis on the sharing of experiences and expression of feelings. The education increased self-esteem, enhanced body image, instilled control, led to more discussions with family members and reduced intrusive thoughts about the illness postintervention and at a 6 month follow-up. No benefits were found of participation in the peer support group. At a 3 year follow-up (Helgeson et al., 2001), the authors found that the benefits of the education intervention were maintained. No benefits were found of the peer discussion, either alone or in combination with the education. In a prediction study (Helgeson et al., 2000), the authors found that educational groups showed greater benefits of physical function among women who lacked social support or had fewer personal resources. The peer discussion groups were helpful for women who lacked support from their partners or physicians, but were harmful for women who had high levels of support.
Lepore and Helgeson (1999) randomly assigned prostate cancer patients, shortly after their cancer treatment, to a psychoeducational support group (n=12) or a control group (n=12). The intervention consisted of six weekly, 1 h 45 min sessions with education about disease and teaching methods of coping with its negative side effects, nutrition, exercise, stress management, communication and intimacy, and follow-up care. Leaders were a nurse and a psychologist, together with an oncologist, a urologist and a nutritionist. Seven of 11 wifes also participated in the group. At postintervention, greater improvements were found in mental health, fewer interpersonal conflicts, larger increases in perceived control over health and functioning, and lower distress associated with cancer-related thoughts.

Antoni et al. (2001) randomised newly diagnosed (surgery within 8 weeks) breast cancer patients to a ten weekly, 2-h sessions intervention (n=47) or a control condition (n=53). Mean age was 50 years. The Cognitive Behavioural Stress Management (CBSM) intervention included emotional expression, cognitive restructuring, training in relaxation, assertiveness, interpersonal conflict resolution, and coping skills. Two psychologists co-led the groups of up to 8 patients. Control patients were invited to participate in a 1-day seminar, including a condensed version of the intervention at approximately 4 months postsurgery. There were no significant interactions between group and repeated measurement, but the prevalence of moderate depression was reduced in the intervention group. Depression remained relatively stable in the control group. Other measures of distress were not affected. However, most patients in the intervention group reported that their lives had changed in positive ways because of the diagnosis of cancer. The authors noted that the levels of distress in this sample were generally low.
Simpson et al. (2001) randomised breast cancer patients (Stage 0-II with active treatment completed) to a group psychosocial intervention \((n=46)\) or a control condition \((n=43)\). Mean age was 49 years. The intervention consisted of six weekly, 1.5 h sessions in groups of 7-10 patients. Progressive muscle relaxation, self hypnosis, stress management techniques, mental imagery, goal setting, and planning and achieving change were the themes of the sessions. A psychiatrist led the groups together with a counsellor who had had breast cancer. At postintervention, patients in the intervention group had less depression, less overall mood disturbance, better quality of life, and fewer psychiatric symptoms than the control group. This remained at a 2 year follow-up. There was also a 23.5% reduction of health care billings in the intervention group.

In summary, the reviewed interventions consists of 6-11 weekly, 1-2 hour sessions and are mostly conducted by a multi-professional team. Sample size in reviewed studies varies between 24-312. Most studies have a short follow-up period, i.e. up to 6 months post intervention. In remaining studies, follow-ups were performed after 9 months (Antoni et al., 2001), 12 months (Berglund et al., 1994), 2 years (Simpson et al., 2001), or 3 years (Helgeson et al., 2001). In some studies, the effects of the intervention were maintained for 6 months (Cain et al., 1986), or had increased by 6 months (Fawzy et al., 1990). In other studies, the immediate benefits began to dissipate 2-3 weeks later (Cunningham & Tocco, 1989), or had disappeared by 6 and 12 months (Berglund et al., 1994b). Only two studies have screened patients for psychological problems (Bottomley et al., 1996; Evans & Connis, 1995). When compared, individual and group interventions have been found to be equally effective (Cain et al., 1986; Fawzy et al., 1996).
Positive effects of group interventions were reported on anxiety (Bottomley et al., 1996; Cain et al., 1986; Cunningham & Tocco, 1989; Johnson, 1982), depression (Antoni et al., 2001; Berglund et al., 1994; Cain et al., 1986; Cunningham & Tocco, 1989; Edelman et al., 1999a; Evans & Connis, 1995; Simpson et al., 2001; Telch & Telch, 1986), mood (Cunningham & Tocco, 1989; Edelman et al., 1999a; Simpson et al., 2001), distress (Fawzy et al., 1990; Lepore & Helgeson, 1999), quality of life (Simpson et al., 2001), self-esteem (Edelman et al., 1999a), physical function (Berglund et al., 1994a; Helgeson et al., 1999), knowledge (Cain et al., 1986; Johnson, 1982), fighting spirit (Berglund et al., 1994; Bottomley et al., 1996) and survival (Fawzy et al., 2003; Fawzy et al., 1993). However, some studies found no effect of the group intervention on distress (Antoni et al., 2001) or survival (Edelman et al., 1999b).

Three meta-analyses have been conducted examining the effects of psychosocial interventions with adult cancer patients (Devine & Westlake, 1995; Meyer & Mark, 1995; Sheard & Maguire, 1999). Devine and Westlake (1995) conducted a meta-analysis on 116 studies of psychoeducational care and found benefits on anxiety, depression, mood, nausea, vomiting, pain and knowledge. Meyer and Mark (1995) analysed 45 studies and found that psychosocial interventions (i.e. cognitive-behavioural interventions, informational and educational treatment, non-behavioural counselling or psychotherapy, social support by non-professionals and unusual treatments, such as music therapy) had positive effects on emotional and functional adjustment, and treatment- and disease-related symptoms in adult cancer patients. No effect was found on medical measures, e.g. tumour response to chemotherapy or tumour progression. Sheard and Maguire (1999) analysed the effects of psychological interventions on anxiety (19 studies) and depression (20 studies). Their findings suggested that the interventions may have moderate clinical effects on anxiety but not on depression. Interventions targeted at those identified at risk of, or suffering significant psychological...
distress were associated with clinically powerful effects relative to unscreened patients. Group interventions, particularly psychoeducational, were found to be at least as effective as individual therapy.

The authors of these meta-analysis point out that the studies included show considerable variation with respect to subjects, stage of disease, settings, type of intervention, intervention modality, outcome measures, theoretical basis, therapist expertise, amount of therapy given and research designs. Some benefits are gained from these interventions, but the effect sizes are small and the studies lack adequate statistical power due to relatively small groups (Meyer & Mark, 1995; Sheard & Maguire, 1999).

Other methodological weaknesses (e.g. over-representation of women patients in samples, poor descriptions of samples, lack of clearly defined interventions, lack of information about therapist characteristics and training, failure to use standardised assessment tools), have been pointed out in recent reviews of the psycho-oncological literature (Bottomley, 1997b, Sellick & Crooks, 1999). However, Sheard and Maguire (1999) identified three trials of group psycho-educational courses with large reductions of anxiety and depression (Fawzy et al., 1996; Johnson, 1982; Telch & Telch, 1986). These trials were all conducted in the USA and have relatively small sample sizes (80, 52 and 41 patients). The two latter include pre- and posttreatment assessments only.

Some patients may have problems to attend weekly sessions due to travel problems or work. Cunningham et al. (1995) randomised patients with mixed diagnoses to a six weekly, 2 h session programme or a weekend course. The patients were at different stages of cancer, but all requested admission to a psychoeducational programme. Mean age was 49 years. The two
formats were found to be equivalent in their overall effects on mood and quality of life up to the 19 week follow-up.

The Internet provides a novel set of tools that may be of help to cancer patients (Sharp, 2000). Lieberman et al., (2003) presented findings from a study of 67 women with breast cancer who had participated in electronic support groups. At the end of the 16-session weekly intervention, patients had significantly reduced depression, reactions to pain, and they also demonstrated a trend toward increases on two subscales of a posttraumatic growth inventory. In an interview within 1 month after group termination, 67% of the patients found the group to be beneficial. A large percentage of the women in this study were from rural locations, and thus had limited access to support groups.

Quality of life (QOL)

Traditional endpoints in clinical trials are overall survival, disease-free survival and tumour response. The assessment of QOL has become important since more patients survive or live long with their cancer disease (Sprangers, 2002). Assessment of QOL is potentially important, also in clinical practice, since it may be helpful in the planning of care together with the patient. We need to know more about how diseases and treatments affect the overall, long-term functioning of cancer patients.

Health related quality of life (HRQOL) refers to a multidimensional concept which comprises perceptions of negative as well as positive aspects of at least four dimensions: physical, emotional, social and cognitive function (Aaronson et al., 1993). In addition, more specific components are often included such as sexuality, body image, spirituality, economic status, role performance and self-esteem. There is an international consensus that HRQOL is a
subjective evaluation (Cella & Tulsky, 1990). That is, the patients themselves are the best judges of their own HRQOL.

The EORTC QLQ-C30 questionnaire (Aaronson et al., 1993) was used for assessment of various aspects of QOL in the present study.

**Anxiety and depression**

Symptoms of anxiety and depression are considered normal responses to a crisis, and usually begin to resolve within 1-2 weeks after a cancer diagnosis (Massie & Holland, 1989). The prevalence of anxiety and depression in cancer patients varies widely between studies. This may be due to differences in cancer sites, stages of the disease, and variations in the tools used for assessment (Bottomley, 1997a; McDaniel et al., 1995; van't Spijker et al., 1997). In an often referred study by Derogatis and colleagues (1983), the prevalence of psychiatric disorders among cancer patients was 47%, using a DSM-III diagnosis. Approximately 85% of these had depressive or anxious symptoms as their central problem. This study was performed almost 20 years ago, why its relevance today can be seriously questioned.

In a meta-analytic review of 58 studies performed between 1980 and 1994, van’t Spijker and co-workers (1997) concluded that the extent of psychological and psychiatric problems is significantly less in cancer patients than in psychiatric patients. Cancer patients were not significantly more anxious, but more depressed than a reference group from the normal population. This difference was not significant if the meta-analysis was restricted to studies published after 1987. With the exception of depression, anxiety has been reported to be lower in cancer patients than in other groups of medical patients with mixed diagnoses. Anxiety decreased significantly over time, while no decrease was found for depression. Interestingly,
in studies published before 1988, higher levels of depression, anxiety and general psychological distress were reported than was the case for studies published later.

Nordin and Glimelius (1997) reported that the overall levels of anxiety and depression were low in newly diagnosed gastrointestinal cancer patients. On the Hospital Anxiety and Depression Scale (HADS), a total of 17% scored as "doubtful cases" or "cases" on the anxiety scale and 21% did so on the depression scale. As assessed with the HADS (cases, ≥ 11), the prevalence of anxiety and depression in 716 cancer patients in Norway was 13% and 9%, respectively (Aass et al., 1997). If the category of “doubtful cases” had been used, the corresponding numbers had been 31% for anxiety and 20% for depression. A total of 13% of patients with gastrointestinal cancer evidenced depression, whereas only 5% of breast and urological cancer patients were thus categorised. These authors also found that anxiety and depression were associated with an impaired ability to continue professional work and/or daily life activities, impaired social life, previous psychiatric problems, impaired physical function, fatigue and pain. Women patients reported significantly more anxiety than did men. Age or gender were not significantly related to the occurrence of depression. Sellick and Crooks (1999) found that prevalence rates for major depression increased with higher levels of physical disability, advanced illness, and pain. Stark and co-workers (2002) performed multivariate analyses and found that female sex and negative aspects of social support (inadequate support or problems emanating from those providing support) were associated with anxiety disorder.

In a study of the same sample as in the present thesis including breast, colorectal, gastric or prostate cancer patients, Nordin et al. (2001) found that mean levels of anxiety and depression
decreased significantly over time for the whole group. Anxiety did so for all diagnostic
groups, but there was no decrease of depression in patients with gastric or prostate cancer.

The importance of detecting psychological morbidity and treating symptoms of distress, even
when they do not achieve diagnostic criteria for defined psycho-pathological entities, was
shown by Koller et al. (1996). Patients’ reports of physical symptoms and global quality of
life were more closely associated with a negative emotional state than with physical health
status as determined by physicians.

It should be noted that depression and anxiety may be effects of tumoural activity, e.g.
cerebral metastases and metabolic impairments such as hypercalcaemia, or represent side-
effects of treatment (depression at interferon treatment). Anxiety and depression may also
have a high prevalence among patients who have a previous personal history of psychiatric
disorder, or who have a problematic social situation (Hughes, 1987). Untreated depression in
the presence of cancer may result in more frequent clinic visits, increased costs, extended
hospitalisation, reduced compliance (cited in McDonald et al., 1999) and a reduced quality of
life.

In the present study, the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith,
1983) was used for assessment of anxiety and depression.

**Intrusion and avoidance**

Clinical studies have revealed two common responses to stressful events: intrusion and
avoidance. Intrusion involves unbidden thoughts and images, troubled dreams, strong pangs
or waves of feelings, and repetitive behaviour. Avoidance involves ideational constriction,
denial of meanings and consequences of the event, blunted sensation, behavioural inhibition or counter-phobic activity, and awareness of emotional numbness (Horowitz et al., 1979).

Studies have demonstrated high levels of intrusion and avoidance in cancer patients (Kaasa et al., 1993; Wettergren et al., 1999). Women had higher score on intrusion than men, but there were no clear differences within diagnosis groups (Kaasa et al., 1993). A reduced physical performance have been found to be closely related to psychological distress (Kaasa et al., 1993; Manne et al., 2001).

The Impact of Event Scale (IES) (Horowitz et al., 1979) was used to assess intrusion and avoidance in the present study.

In summary, there is evidence that the diagnosis and treatment of cancer affects at least some aspects of HRQOL negatively. Also, a proportion of cancer patients develop psychiatric and psychological symptoms as a result of the disease.

Coping

Theories of coping postulate that an individual’s reaction to a stressful situation is moderated by his/her ability to handle the threat and the resulting reactions (Lazarus, 1993). The relevance of coping for understanding psychological well-being among cancer patients has been demonstrated earlier (Nordin & Glimelius, 1998).

Lazarus (1993) has classified coping strategies into two major groups: problem-focused coping which denotes efforts to actively or directly eliminate or solve problems, and emotion-focused coping which not is directed towards solving a problem but rather to alter the
reactions to the problem. Examples of the former are information-seeking and goal setting, and of the latter, hopeful thinking, acceptance and denial. Neither of these two types of coping strategies is consistently superior to the other. However, problem-focused coping may be more helpful when the circumstances are controllable, and emotion-focused coping is more helpful when the circumstances are uncontrollable (Folkman, 1984). A coping strategy that is effective in one context may not necessarily be effective in another situation or at a different time.

Coping is sometimes enhanced by sharing concerns with others. Fawzy et al. (in Baum and Andersen, p. 258) have suggested that group intervention patients have the opportunity to practice their coping skills in the group. In this way, patients may receive firsthand information on how to deal with problems that each of them is facing. It may be more helpful and have a more enduring effect to receive coping information from fellow patients, rather than from a health care professional.

**Monitoring and Blunting**

An important aspect of the ability to cope with a potentially serious illness is the desire for information about its various facets (Johnson et al., 1996). Patients vary in how they perceive and respond to their medical problems, their needs for information, control, and their need for psychosocial intervention. It has been concluded that the cognitive coping style used in a given situation is related to the level of psychological distress, such as anxiety (Davis et al., 1994). Two coping styles have been distinguished in relation to information (Miller, 1987). Monitoring involves a tendency to actively seek information about the stressful event. Blunting means that the individual tends to seek distraction from the threatening situation. Overall, a Blunting orientation is associated with less anxiety than is Monitoring.
It has been proposed that in stressful situations, it is important to adjust the information given to the individual’s coping style (Miller & Mangan, 1983). Thus, individuals generally fare better when the level of information they receive is consistent with their coping style, i.e., low monitors/high blunters fare better with minimal information and high monitors/low blunters tend to fare better with more voluminous information (Miller, 1988). This proposition has been confirmed in several patient populations, e.g. in women about to undergo gynaecologic surgery (Steptoe & O'Sullivan, 1986), cardiac catheterisation patients (Watkins et al., 1986), and patients visiting a primary care setting for acute medical problems (Miller et al., 1988). In these groups, high monitors/low blunters appear to desire more voluminous and detailed levels of information and preparation than do low monitors/high blunters.

Monitors have been shown to experience a significantly higher incidence rate and longer episodes of chemotherapy-induced nausea than blunters (Gard et al., 1988; Lerman et al., 1990). This was true despite the fact that monitors used more antiemetic medication than blunters (Gard et al., 1988). Blunters were less anxious than monitors (Lerman et al., 1990; Steptoe et al., 1991). Miller (1995) has pointed out that monitors who are pessimistic about their future or face uncontrollable medical situations may not just need more information, but also more emotional support to help them deal with their disease.

The Miller Behavioural Style Scale (MBSS) (Miller, 1987) was used to assess Monitoring/Blunting in the present study.

**The Support-Care-Rehabilitation-project**

The present thesis is based on parts of a prospective, randomised study, the ”Support-Care-Rehabilitation” (SCR)-project. Between October 1st 1993 and December 31st 1995, a
consecutive series of patients in Uppsala county (289,000 inhabitants) were approached. Patients under medical examination for a suspected breast cancer, and patients with newly diagnosed (<3 months) breast, gastrointestinal (colorectal or gastric) or prostate cancer were included. The aim of the SCR-project was to study the effectiveness of two interventions, "Individual Support" (IS) and "Group Rehabilitation" (GR), and their combination (ISGR) for relieving psychosocial problems, and nutritional difficulties at the time of cancer diagnosis and initial treatment (IS), and for the prevention of later psychosocial and nutritional problems during rehabilitation (GR). Furthermore, the aim was to develop a co-ordinated model of cancer care, characterised by increased continuity of care. Using a two-by-two design, patients were randomly assigned to one of four alternatives: 1. "Individual Support" (IS); 2. "Group Rehabilitation" (GR); 3. A combination of "Individual Support" and "Group Rehabilitation" (ISGR); and 4. Standard Care (SC). All patients were monitored for two years, from diagnosis through rehabilitation and/or palliative phases.

**Individual Support (IS)**

The IS started as early as possible after diagnosis and consisted of three types of support:

1. **Individual Psychological Support (IPS).** The IPS was designed to identify patients’ individual needs, and to help them handle problems arising from the diagnosis and medical treatments. The patients were contacted by phone by one of four psychologists in the project, and were invited to a first session. After having assessed problems and the patient’s life situation, the psychologist suggested appropriate psychological interventions based on the patient’s needs and further sessions were jointly decided on. The techniques used in treatment were derived from psychosocial oncology and cognitive behavioural therapy. The contact was usually terminated if no problems were identified, but the patient
had the opportunity to call the psychologist if problems should arise. The IPS has been described and evaluated by Hellbom (Hellbom, 2001).

(2) Intensified Primary Health Care (IPHC). The IPHC comprised routines to improve home care nurses’ and general practitioners’ (GP’s) possibilities to support and monitor cancer patients. After giving informed consent, the patient was referred to the home care nurse responsible for the district where the patient lived. The frequency, timing, duration and contents of the IPHC contacts were decided jointly by the home care nurse and the patient. The patient’s GP was informed about the cancer diagnosis and the referral to the home care nurse, but follow-up contacts with the GP had to be initiated either by the GP or the patient. An extended information routine was implemented, in that the GPs and home care nurses were provided with copies of the medical records each time the patient was discharged from the specialist clinic after a period of inpatient care, or had visited the specialist outpatient clinic. During the study period, education in cancer care (diagnostics and treatments of the cancer diseases, medical aid, pain, nausea/vomiting and diet management, psycho-social support and palliative care) was arranged for all home care nurses and GPs in Uppsala County. The home care nurses with patients randomised to IS were also offered supervision by a multi-professional oncology team consisting of members of the project group. The IPHC has been described and evaluated by Johansson (Johansson, 2000).

(3) Patients with colorectal or gastric cancer were also offered Nutritional Support (NS) by a dietician. The NS was based on the individual patient’s nutritional intake and preferences and should provide enough for the patient’s nutritional requirements. The dietician contacted the patient as soon as possible after diagnosis and made a dietary assessment
(24-h recall). The patient’s living area determined whether the contact was made face-to-face or by telephone. Family members were offered an opportunity to talk to the dietician for advice about how to support the patient. The patients were contacted again after 3, 6, 12 and 24 months. Additional contacts were provided if necessary. The NS has been described and evaluated by Persson (Persson, 2002).

**Group Rehabilitation (GR)**

The GR was an eight-session, structured intervention starting approximately 4 months after diagnosis. It will be described in detail below.

**Standard Care (SC)**

SC consisted of regular follow-up visits at the outpatient clinics (surgical or oncological, depending on diagnosis, stage, and treatment). All patients, independent of randomisation group, had the opportunity to contact health care staff when needed, e.g. counsellor, dietician, hospital physician, GP, or primary care nurse. Psychologists were not available at the surgical and oncological clinics. Some SC patients were referred to home care nurses and GPs, although this was rare (Johansson et al., 1999), but the extended information routine and the supervision were not provided for these patients. Contact with a dietician was not offered routinely unless the patient’s physician or other medical staff judged this to be necessary. There were no regular group rehabilitation programs or support groups available at the surgical and oncological clinics.
AIMS

The overall aims are to evaluate the effects of the SCR Group Rehabilitation (GR) intervention for patients with breast, gastrointestinal or prostate cancer and to explore the extent to which the patient’s coping style (monitoring, blunting) modulates the effects of the GR. An additional aim is to investigate to what extent some aspects of health-related quality of life (HRQOL) [Physical Functioning (PF), Emotional Functioning (EF) and Global Quality of Life (QoL)] one year after diagnosis can be predicted on the basis of data collected at diagnosis. These HRQOL aspects were chosen since they may reflect the need for further rehabilitation.

Specific aims were:

1. To investigate patients’ ratings of satisfaction with the GR, perceived benefits and the perceived difficulty to understand and apply the techniques taught during the GR (Study I).

2. To compare participation rates, satisfaction, perceived benefits and perceived difficulty of the GR techniques between diagnoses, genders, age groups (<65 yr., ≥65 yr.) and between groups of patients offered only GR and those offered a combination of ISGR (Study I).

3. To evaluate the short- and long-term effects of the GR programme on quality of life, anxiety, depression, intrusion and avoidance in a randomised design (Study II).

4. To investigate the extent to which the Miller Behavioural Style Scale (MBSS) (Monitors vs. Blunters) can be used to differentiate cancer patients who are likely to benefit from a
rehabilitation effort with a strong information component (GR) from those who are not (Study III).

5. To explore the extent to which patients’ medical status, socio-demographic status, level of outside home activity, emotional problems, and general satisfaction with life at diagnosis can predict aspects of HRQOL (i.e. PF, EF, and global QoL) one year after diagnosis (Study IV).
METHODS

Patients

Between October 1st 1993 and December 31st 1995, a consecutive series of patients under medical examination for a suspected breast cancer, and patients with newly diagnosed (<3 months) breast (n=337), colorectal (n=169), gastric (n=52) or prostate (n=238) cancer met the criteria for inclusion in the SCR-project. Exclusion criteria were a constant need for hospital care (Karnofsky performance status <40), an earlier cancer diagnosis (except cervix cancer in situ and basal cell carcinoma) and inability to speak or understand Swedish. In addition, patients participating in an ongoing clinical trial (SPCG IV) were excluded. In that study, patients (n=59) with localised prostate cancer (T 1-2, N0, M0) were randomised between radical prostatectomy and expectancy. Participation in the SCR-project was judged to be a potential threat to the integrity of the quality of life measurements of the SPCG IV.

Of the 796 patients who met the criteria for inclusion, 9 % [n=73 (breast n=6, colorectal n=15, gastric n=7, prostate n=45)] were missed due to uncertainty about the correct diagnosis or administrative failure. Seventy-three percent (n=527) of the available patients accepted participation. Twenty percent (n=65) of the patients with breast cancer, 29% (n=57) of those with gastrointestinal cancer, and 38 % (n=74) of those with prostate cancer rejected participation (Table 1). Reasons for not participating were “not interested” (n=75, 38%), ”no need of or already having enough support” (n=51, 26%), ”too far to travel” (n=23, 12%), ”no wish to participate in research” (n=22, 11%), ”too ill/tired” (n=16, 8%), ”too time consuming” (n=7, 4%), and ”previous negative experiences of contacts with primary care or psychologist” (n=2, 1%). Patients who rejected participation were significantly older (mean 71.0 yr., SD 11.9) than those who accepted participation (mean 62.8 yr., SD 13.5) (t=7.50, df=721,
p<0.001). This difference was evident in all diagnostic groups. Figure 1 presents the flow of patients during the 2-year study period.

Table 1. The Support-Care-Rehabilitation-project. Overview of eligible, missed, non-participating, participating, excluded, benign breast cancer patients, and GI cancer patients with known metastasis at inclusion.

<table>
<thead>
<tr>
<th></th>
<th>Breast cancer</th>
<th>Colorectal cancer</th>
<th>Gastric cancer</th>
<th>Prostate Cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible*</td>
<td>337</td>
<td>169</td>
<td>52</td>
<td>238</td>
<td>796</td>
</tr>
<tr>
<td>Missed*</td>
<td>6</td>
<td>15</td>
<td>7</td>
<td>45</td>
<td>73</td>
</tr>
<tr>
<td>Non-participating*</td>
<td>65</td>
<td>49</td>
<td>8</td>
<td>74</td>
<td>196</td>
</tr>
<tr>
<td>Participating</td>
<td>266</td>
<td>105</td>
<td>37</td>
<td>119</td>
<td>527</td>
</tr>
<tr>
<td>Excluded</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Benign breast cancer</td>
<td>42</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>42</td>
</tr>
<tr>
<td>Known metastasis at inclusion (GI cancer randomised between IS and SC only)</td>
<td>-</td>
<td>18</td>
<td>21</td>
<td>-</td>
<td>39</td>
</tr>
<tr>
<td>Total (Rehabilitation/Control)</td>
<td>223</td>
<td>86</td>
<td>15</td>
<td>118</td>
<td>442</td>
</tr>
</tbody>
</table>

* differ slightly from numbers in thesis by Hellbom (Hellbom, 2001) and Johansson (Johansson, 2000)
Figure 1. The "Support-Care-Rehabilitation"-project.

Total eligible n=796

↓

Missed n=73

Approached n=723

↓

Declined participation n=196
Known metastatic disease n=39\(^a\)

Randomised n=488

↓

Excluded n=4\(^b\)
Benign n=42\(^c\)

Rehabilitation n=221

ISGR (n=117) + GR (n=104)

Declined participation before start of intervention (n=26)

↓

Baseline assessment\(^d\), n=195
(Studies II and III)

Declined participation n=5
Died n=2

3 months assessment n=188

Declined participation n=1
Died n=6

9 months assessment n=181

Died n=10

21 months assessment n=171

\(^a\) Gastrointestinal cancer patients with known metastatic disease at the time of diagnosis were only randomised between IS and SC

\(^b\) Erroneous diagnosis (n=2), delay of more than three months from diagnosis to inclusion (n=1), and dementia (n=1)

\(^c\) Patients who were under medical investigation for a suspected breast cancer were informed that GR would be an option only if surgery confirmed a cancer diagnosis

\(^d\) 3 months after randomisation

Control n=221

IS (n=115) + SC (n=106)

Declined participation before start of intervention (n=23)

↓

Baseline assessment\(^d\), n=198
(Studies II and III)

Declined participation n=5

3 months assessment n=193

Declined participation n=4
Died n=5

9 months assessment n=184

 Declined participation n=5
Died n=6

21 months assessment n=173

Four patients were excluded from the SCR-project after randomisation [erroneous diagnosis (n=2), delay of more than 3 months from diagnosis to inclusion (n=1), dementia (n=1)].
Patients who were found to have a benign breast tumour after inclusion (n=42) were excluded from the present analyses since they had been informed at inclusion that GR would not be considered if the tumour was benign. Gastrointestinal cancer patients (n=39) with known metastases at inclusion were randomised only between IS and SC since they not were eligible for GR due to a too short period of expected survival (Table 1). These patients were excluded in all studies except Study IV.

The project was approved by the Research Ethics Committee at the Faculty of Medicine, Uppsala University.

Inclusion and randomisation

Inclusion took place at the three hospitals in Uppsala county with surgical and/or oncological receptions and wards. A research nurse checked the waiting lists for new patients at least once a week. To prevent missing patients, all cancer reports to the regional oncological centre were checked monthly. After permission from the patient’s physician, information about the SCR-project was given, both orally and in writing. Patients were also informed that they were free to discontinue their participation at any time, without having to give a reason for this, and that withdrawal would not affect their medical treatment or care. Information about the project was given as soon as possible after the cancer diagnosis (within 3 months), or after a suspicion of breast cancer that demanded surgery.

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1 In Sweden, reporting of all new cancer cases to a regional registry is compulsory for all physicians. Furthermore, pathologists and cytologists separately report every cancer diagnosis based on histological and cytological specimens and autopsies. The reporting is regulated by the National board of Health and Welfare (SOSFS(M) 1984:32).
Patients who consented to participate were randomised to one of four alternatives: 1. "Individual Support" (IS); 2. "Group Rehabilitation" (GR); 3. A combination of "Individual Support" and "Group Rehabilitation" (ISGR); or 4. Standard Care (SC). In order to obviate any bias in randomisation, this procedure was carried out independently by an oncological statistics centre (computer generated allocation schedule). The project personnel who included the patient telephoned the statistics centre to register each patient and be told of the randomisation arm assigned. Patients with suspected breast cancer were informed that if the tumour was benign, GR would not be considered. Patients with advanced gastrointestinal cancer (expected survival of <6 months) were randomised only between IS and SC since the GR was planned to start approximately 3-4 months after inclusion. Randomisation was stratified for diagnosis (breast, colorectal, gastric, prostate), and stage of disease [i.e. for breast cancer: <55 yr./≥55 yr./advanced disease (inoperable, known metastasis), and for colorectal, gastric and prostate cancer: no known metastasis/metastasis]. Patients were informed about their group allocation after they had completed the inclusion questionnaires. Sociodemographic data are presented in Table 2. Medical background data are presented in Table 3.
Table 2. Sociodemographic data for patients in the Rehabilitation and Control groups (n=442).

<table>
<thead>
<tr>
<th></th>
<th>Rehabilitation</th>
<th>Control</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=111</td>
<td>n=112</td>
<td>n=223</td>
</tr>
<tr>
<td><strong>Age, years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast cancer</td>
<td>58.0 (13.8)</td>
<td>56.9 (13.0)</td>
<td>57.4 (13.4)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>32-87</td>
<td>32-90</td>
<td>32-90</td>
</tr>
<tr>
<td>Range</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinala</td>
<td>n=51</td>
<td>n=50</td>
<td>n=101</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>68.5 (10.9)</td>
<td>69.1 (11.4)</td>
<td>68.8 (11.1)</td>
</tr>
<tr>
<td>Range</td>
<td>45-87</td>
<td>41-88</td>
<td>41-88</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>n=59</td>
<td>n=59</td>
<td>n=118</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>72.4 (6.8)</td>
<td>69.2 (7.6)*</td>
<td>70.8 (7.4)</td>
</tr>
<tr>
<td>Range</td>
<td>57-85</td>
<td>53-86</td>
<td>53-86</td>
</tr>
<tr>
<td>All patients</td>
<td>n=221</td>
<td>n=221</td>
<td>n=442</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>64.2 (13.3)</td>
<td>62.9 (12.9)</td>
<td>63.6 (13.1)</td>
</tr>
<tr>
<td>Range</td>
<td>32-87</td>
<td>32-90</td>
<td>32-90</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>93 (42)</td>
<td>88 (40)</td>
<td>181 (41)</td>
</tr>
<tr>
<td>Female</td>
<td>128 (58)</td>
<td>133 (60)</td>
<td>261 (59)</td>
</tr>
<tr>
<td><strong>Social status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/cohabitant</td>
<td>152 (69)</td>
<td>157 (71)</td>
<td>309 (70)</td>
</tr>
<tr>
<td>Single, divorced, widowed</td>
<td>63 (28)</td>
<td>55 (25)</td>
<td>118 (27)</td>
</tr>
<tr>
<td>Missing data</td>
<td>6 (3)</td>
<td>9 (4)</td>
<td>15 (3)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>95 (43)</td>
<td>93 (42)</td>
<td>188 (43)</td>
</tr>
<tr>
<td>Grammar/Junior secondary school</td>
<td>56 (25)</td>
<td>56 (25)</td>
<td>112 (25)</td>
</tr>
<tr>
<td>College/university</td>
<td>56 (25)</td>
<td>52 (24)</td>
<td>108 (24)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (4)</td>
<td>11 (5)</td>
<td>19 (4)</td>
</tr>
<tr>
<td>Missing data</td>
<td>6 (3)</td>
<td>9 (4)</td>
<td>15 (3)</td>
</tr>
</tbody>
</table>

*a colorectal cancer (n=86)+gastric cancer (n=15)
*p<0.05
Table 3. Diagnoses, stages and medical treatment of patients in the Rehabilitation and Control groups.

<table>
<thead>
<tr>
<th></th>
<th>Rehabilitation</th>
<th>Control</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Breast</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening*</td>
<td>48 (43)</td>
<td>65 (58)</td>
<td>113 (51)</td>
</tr>
<tr>
<td>Clinical</td>
<td>63 (57)</td>
<td>47 (42)</td>
<td>110 (49)</td>
</tr>
<tr>
<td>Premenopausal</td>
<td>39 (35)</td>
<td>42 (38)</td>
<td>81 (36)</td>
</tr>
<tr>
<td>Postmenopausal</td>
<td>72 (65)</td>
<td>70 (62)</td>
<td>142 (64)</td>
</tr>
<tr>
<td><strong>Preop chemotherapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>100 (90)</td>
<td>103 (92)</td>
<td>203 (91)</td>
</tr>
<tr>
<td>Yes, FEC^a</td>
<td>11 (10)</td>
<td>9 (8)</td>
<td>20 (9)</td>
</tr>
<tr>
<td><strong>Surgery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sector resection</td>
<td>85 (76)</td>
<td>91 (81)</td>
<td>176 (79)</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>25 (23)</td>
<td>21 (19)</td>
<td>46 (21)</td>
</tr>
<tr>
<td>no surgery</td>
<td>1 (1)</td>
<td>1 (0.5)</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td><strong>Post operative treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy (RT)</td>
<td>49 (45)</td>
<td>53 (47)</td>
<td>102 (46)</td>
</tr>
<tr>
<td>Hormonal treatment</td>
<td>5 (5)</td>
<td>2 (2)</td>
<td>7 (3)</td>
</tr>
<tr>
<td>RT+chemotherapy ±hormonal</td>
<td>27 (24)</td>
<td>26 (23)</td>
<td>53 (24)</td>
</tr>
<tr>
<td>RT+hormonal treatment</td>
<td>20 (18)</td>
<td>19 (17)</td>
<td>39 (18)</td>
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<tr>
<td>no treatment</td>
<td>9 (8)</td>
<td>12 (11)</td>
<td>21 (9)</td>
</tr>
<tr>
<td><strong>Gastrointestinal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon</td>
<td>26 (51)</td>
<td>29 (58)</td>
<td>55 (54)</td>
</tr>
<tr>
<td>Rectum</td>
<td>18 (35)</td>
<td>13 (26)</td>
<td>31 (31)</td>
</tr>
<tr>
<td>Gastric</td>
<td>7 (14)</td>
<td>8 (18)</td>
<td>15 (15)</td>
</tr>
<tr>
<td><strong>DUKES (colon and rectum)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>1 (2)</td>
<td>9 (21)</td>
<td>10 (12)</td>
</tr>
<tr>
<td>B</td>
<td>25 (57)</td>
<td>20 (48)</td>
<td>45 (52)</td>
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<tr>
<td>C</td>
<td>16 (36)</td>
<td>10 (24)</td>
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<tr>
<td>D</td>
<td>2 (5)</td>
<td>3 (7)</td>
<td>5 (6)</td>
</tr>
<tr>
<td><strong>Pre-op treatment (rectum)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RT</td>
<td>15 (83)</td>
<td>9 (69)</td>
<td>24 (77)</td>
</tr>
<tr>
<td>RT+chemotherapy</td>
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<td>1 (8)</td>
<td>2 (6)</td>
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<tr>
<td>none</td>
<td>2 (11)</td>
<td>3 (23)</td>
<td>5 (16)</td>
</tr>
<tr>
<td><strong>Radical surgery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>45 (88)</td>
<td>44 (88)</td>
<td>89 (88)</td>
</tr>
<tr>
<td>No</td>
<td>6 (12)</td>
<td>6 (12)</td>
<td>12 (12)</td>
</tr>
<tr>
<td><strong>Post-op treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjuvant</td>
<td>13 (25)</td>
<td>8 (16)</td>
<td>21 (21)</td>
</tr>
<tr>
<td>Palliative</td>
<td>5 (10)</td>
<td>2 (4)</td>
<td>7 (6)</td>
</tr>
<tr>
<td>None</td>
<td>33 (65)</td>
<td>40 (80)</td>
<td>73 (72)</td>
</tr>
</tbody>
</table>
Table 3, continued.

<table>
<thead>
<tr>
<th></th>
<th>Rehabilitation n (%)</th>
<th>Control n (%)</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prostate</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metastases at inclusion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>50 (85)</td>
<td>50 (85)</td>
<td>100 (85)</td>
</tr>
<tr>
<td>Yes</td>
<td>9 (15)</td>
<td>9 (15)</td>
<td>18 (15)</td>
</tr>
<tr>
<td>First line treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watchful waiting</td>
<td>33 (56)</td>
<td>23 (39)</td>
<td>56 (47)</td>
</tr>
<tr>
<td>Prostatectomy</td>
<td>8 (14)</td>
<td>6 (10)</td>
<td>14 (12)</td>
</tr>
<tr>
<td>RT</td>
<td>6 (10)</td>
<td>11 (19)</td>
<td>17 (14)</td>
</tr>
<tr>
<td>Hormonal</td>
<td>12 (20)</td>
<td>19 (32)</td>
<td>31 (26)</td>
</tr>
</tbody>
</table>

*p<0.05
a FEC = fluorouracil, epirubicin, cyclophosphamide

The Group Rehabilitation (GR) intervention

The overall goal of the GR was to improve patients’ ability to cope with problems occasioned by disease and treatment and to improve their quality of life. The GR was based on the principles of cognitive-behavioural therapy (CBT). The GR is a group model developed on the basis of experiences from the "Starting again"-programme at Radiumhemmet, Karolinska Hospital in Stockholm (Berglund, 1995). In that study, there was no reduction of psychological distress. For that reason the present GR intervention comprises more sessions and a more structured CBT component based on APT (Moorey & Greer, 1989).

The intervention was designed to start approximately three months after randomisation. The intention was to form diagnose specific groups. Patients randomised to the combination of IS and GR had to complete their individual psychological support before participating in the GR. However, the intensified primary care and the dietician contacts which also formed parts of the IS were continued when needed. Three weeks before the GR started, an invitation letter was mailed to all patients. A few days later, the group leader phoned each patient to have participation confirmed or disconfirmed. If there were travel problems or other practical problems in association with participation, attempts were made to solve these.
The GR comprised eight weekly sessions and one booster session after two months. The 2.5-hour meetings consisted of two parts, one including information or CBT, and one consisting of light physical training and relaxation. One of the informative sessions was dedicated to disease and treatment and one to dietetic issues. The CBT included techniques for handling anxiety, problem solving, discovering and challenging automatic negative thoughts, activity planning and distraction. During all sessions, there were opportunities for patients to discuss their concerns. The physical training comprised techniques for relaxation, breathing techniques and a physical activation programme adjusted to the abilities of the members in each group. A coffee break made informal talk possible. Confidentiality rules were set at the first meeting. An overview of the GR programme is presented in Table 4.

Patients were given written information in advance concerning the content of each session to facilitate learning. In order to encourage application of CBT and physical training techniques in daily life, written assignments were given at every session, one for the CBT part and one for the physical training, e.g. to record automatic negative thoughts and challenge them, and to perform daily relaxation exercises.

All patients who missed sessions had the opportunity to meet the group leader before the next session and received copies of material that had been handed out.
Table 4. Content of the GR programme

1. **Handling anxiety**
   - **Relaxation, lying down**
   - Written assignment: How to handle your anxiety
   - Relaxation, lying down

2. **Activity planning, distraction**
   - **Relaxation, sitting**
   - Written assignment: Diary of daily activities
   - Relaxation, sitting

3. **Discovering automatic negative thoughts**
   - **Light physical training + breathing exercises**
   - Written assignment: Record negative thoughts
   - Relaxation + breathing exercises

4. **Challenging automatic negative thoughts**
   - **Light physical training + relaxation**
   - Written assignment: Challenging automatic negative thoughts
   - Physical training + relaxation

5. **Food and cancer**
   - **Light physical training + relaxation**
   - Written assignment: Record problem or automatic negative thoughts
   - Physical training + relaxation

6. **Physician information**
   - **Light physical training + relaxation**
   - Written assignment: Record problem or automatic negative thoughts
   - Physical training + relaxation

7. **Problem solving related to personal relations**
   - **Light physical training + relaxation**
   - Written assignment: Record problem or automatic negative thoughts
   - Physical training + relaxation

8. **Summary of the programme and conclusion**

   A booster-session was held after 2 months. This session included a summary of the programme and light physical training.

---

**Group leaders**

The CBT sessions were conducted by one of four psychologists who were each responsible for all CBT sessions in a specific group. One was a licensed CBT psychotherapist, and three were pre-doctoral psychologists. The session on information about cancer and treatment was held by a physician (oncologist, surgeon, or urologist) with extensive experience of cancer treatment. A dietician conducted the nutritional support session. The physical training was led by a physiotherapist. The five nurses who acted as group co-leaders at each session, all had
extensive experience of cancer care. The CBT psychotherapist also acted as supervisor for the psychologists and nurses.

**Procedures**

Data were collected by self-administered questionnaires. At inclusion, patients were given the questionnaires together with a prepaid return envelope. For those patients who after the information about the project wanted to think further before deciding about participation, questionnaires were mailed after consent. At assessments 3, 6, 12, and 24 (corresponding to baseline, 3-, 9-, and 21-month assessments in Studies II and III) months after randomisation, patients were contacted by phone by one of the investigators and were given information about how to complete the questionnaires. The questionnaires were then mailed to the patients together with written instructions and a prepaid return envelope. If the questionnaire not had been returned in about a week, the same investigator called back to check that the questionnaires had arrived, or if there was any trouble to complete the questions. The investigators checked the returned questionnaires for incomplete responses and contacted the patient to eliminate these. The questionnaire about participation in and satisfaction with the GR programme was mailed two weeks after GR termination (i.e. after the 8 sessions) to those who had participated. A reminder was sent to all participants after two weeks.

**Questionnaires**

*EORTC QLQ-C30*

The EORTC QLQ-C30 (version 1.0) is a 30-item cancer-specific, multidimensional questionnaire for the assessment of quality of life (Aaronson et al., 1993). Five functional scales are used to assess physical, role, emotional, cognitive and social functioning. Three symptom scales assess fatigue, nausea/vomiting and pain. Six single items concern dyspnoea,
insomnia, appetite loss, constipation, diarrhoea and financial difficulties due to disease or treatment. One scale measures global health status/quality of life. The physical and role functioning items have a dichotomous response scale (yes or no) while the global health status scale is scored from 1 (very poor) to 7 (excellent). All other items have a Likert scale with four possible responses (not at all=1, a little=2, quite a bit=3, and very much=4).

All subscale and individual item responses were linearly transformed to a 0-100 scale in accordance with the EORTC guidelines (Fayers et al., 1997). A higher score represents a higher (“better”) level of functioning, or a higher (“worse”) level of symptoms. The questionnaire is appropriate for self administration (i.e. brief and easy to complete), and is applicable across a range of cultural settings. The average time required to complete the questionnaire is 10 minutes. The time frame is the last week.

*Hospital Anxiety and Depression Scale (HADS)*

The HADS is a self-assessment mood scale developed for assessment of anxiety and depression in somatically ill patients, excluding physical aspects that may be affected directly by disease. It consists of two subscales: one measuring anxiety (7 items) and the other depression (7 items) during the last week. Each item has four possible answers ranging from 0 (no problem) to 3 (high level of problems). The scale range is 0 to 21 (Zigmond & Snaith, 1983). Zigmond and Snaith (1983) have suggested a cut-off point of ≥8 to identify patients with potential clinically significant anxiety and depression, and ≥11 to identify clinically significant cases. In the present study (Study IV), patients with scores ≥8 on either or both of the subscales were classified as cases. The HADS has been found to have sufficient reliability and validity for detecting anxiety and depression in somatically ill patients (Moorey et al., 1991).
Impact of Event Scale (IES)

The IES assesses current subjective distress due to a specific life event (Horowitz et al., 1979), in the present study, the cancer disease. It is a 15-item scale that measures intrusion and avoidance. Intrusion is characterised by unbidden thoughts and/or images of the event, e.g. ”I thought about it when I didn’t mean to”. Avoidance is characterised by denial of meanings and consequences of the event, e.g. ”I tried not to think about it”. The patient is asked to estimate the frequency of the phenomena described in each item during the last week on a four-point scale ranging from ”not at all” to ”often”. Scores are obtained by assigning the weights 0, 1, 3 and 5 to the four response alternatives. The subscales have a maximum of 35 for intrusion, and 40 for avoidance. The level of distress is considered to be low at a score of 0-8, medium for 9-19, and high for 20 or above. The reliability and validity of the IES have recently been evaluated and it was concluded that its psychometric properties are satisfactory (Joseph, 2000; Sundin & Horowitz, 2002).

Inclusion Questionnaire (InQ)

At inclusion, each patient was asked to complete an Inclusion Questionnaire (InQ) developed for the SCR-project. It contains questions about the socio-demographic situation (level of education, work/retirement, marital status, number and age of children, family income before taxes, housing situation, smoking habits), as well as questions about normal and actual weight, and comorbidity (hypertension, heart disease, stroke, chronic bronchitis, asthma, arthritis, epilepsy, diabetes, goitre, ulcer, gall-stones, liver disease, hernia). The patient was asked to indicate whether or not a physician had treated him/her for one or more of these medical conditions during the last year, earlier or never. Furthermore, questions from “The Göteborg Quality of Life Instrument” (Tibblin et al., 1990) and the “Interview Schedule for Social Interaction” (Orth-Gomer et al., 1993) were included. These are described below.
The Göteborg Quality of Life Instrument (GQLI)

The GQLI was developed to assess subjective well-being in nationally representative samples of men born in 1913 and 1923. From 1963 to 1981, a series of studies were performed to investigate the development of chronic diseases in these samples (Tibblin et al., 1990). The patient is asked to rate his/her perceived satisfaction in a number of areas (home and family situation, housing, economy, health, spare time, vision, hearing, memory, physical condition, appetite, mood, energy, patience, self-confidence, sleep) on a seven-grade Likert-scale (Not at all satisfied – Very satisfied). The maximum of 105 points indicates a high Well-being. The Well-being scale can be divided into the subscales Social (home and family situation, housing, economy, health, vision), Physical (spare time, hearing, memory, physical condition, appetite, mood), and Mental Well-being (energy, patience, self-confidence, sleep).

The GQLI also contains questions concerning activity level at home (10 items), outside the home (14 items) and socially (8 item). The patient is asked to indicate how often he or she has engaged in such activities during the previous year, using a three-grade scale (Often-regularly, Once or twice, Never). The ratings are summed, giving a maximum of 20 indicating a high home activity level, 28 a high outside home activity level, and 16 a high social activity level. Only the outside home and social activity level scales were used in the present thesis. The scales were modified for the SCR-project and combined to an outside home activity scale. The following activities from the original scales were included: athletic – gymnastic activities, swimming – bathing, cycling - skiing - skating, attend sports events, restaurant dining, dancing, travelling in Sweden, travelling abroad, and visiting association meetings. Furthermore, a few items were altered (i.e. forest walks was added to the original item hunting and fishing; items about theatre, concert, and cinema were combined to a single item; visiting relatives and visiting friends were combined). This resulted in a scale with a total of
12 items and a maximum score of 36 indicating a high outside home activity level. The scale had a Chronbach alpha of 0.75 in the Study IV-sample.

*Interview Schedule for Social Interaction (ISSI)*

An abbreviated version of the original ISSI (Henderson et al., 1980) was used. This has been translated and evaluated by Orth-Gomér and co-workers (Orth-Gomer et al., 1993). The abbreviated ISSI consists of two subscales: Availability of Attachment (AA) and Availability of Social Integration (ASI). In the present thesis, only the ASI was used (Study IV). The ASI (6 items) describes quantitative characteristics of the extended social network and its function: number of people with whom the respondent shares interests, number of people met during an ordinary week, number of friends who at any time would come and visit the respondent at home and who wouldn’t be embarrassed if it was untidy, number of friends or family members with whom the respondent can talk freely, someone available whom the respondent can ask small favours, and someone available - apart from family – to whom the respondent can turn in times of difficulties. Four of the questions are scored on a six-grade Likert-scale (0-5) and the remaining two have a No/Yes format giving a maximum score of 22 which reflects a high level of social integration. The scale had a Chronbach alpha of 0.76 in the Study IV-sample.

*Miller Behavioural Style Scale (MBSS)*

The MBSS (Miller, 1995) is one of the most widely used scales for identifying Monitors (information seekers) and Blunters (information avoiders). It describes four threatening scenarios of an uncontrollable nature, and the patient is instructed to imagine her/himself in these contexts: at the dentist, taken hostage by a group of armed terrorists, the threat of job loss, and flying in an aeroplane when something goes wrong. Patients are asked to select all
response alternatives that apply to them among eight behaviours related to each situation. Four items are related to Monitoring and four to Blunting, forming two subscales. Summing all items endorsed on the Monitoring subscale yields the Monitoring score, and those on the Blunting scale the Blunting score. High and low Monitors and Blunters are defined by dichotomising the distribution at the mean (Miller & Mangan, 1983) or at the median (Steptoe & O'Sullivan, 1986). Thus, four combinations of coping strategies are possible: high Monitor/low Blunter, low Monitor/low Blunter, high Monitor/high Blunter, and low Monitor/high Blunter. The sum score, derived by subtracting the total Blunting score from the total Monitoring score, was used in Study III (except when reporting frequencies of high/low Monitoring and Blunting). The mean value for the sum score scale was 4.10, sd 3.72 (median 4) and patients scoring ≥4 were categorised as Monitors and those scoring below as Blunters.

The MBSS has been found to have adequate test/retest reliability, and scores are generally not related to age, education, or medical background variables (Miller, 1995).

**Questionnaire on patient participation and satisfaction with the GR**

A 30-item questionnaire was developed in the SCR-project for the assessment of patients’ participation in and satisfaction with the GR. Patients were asked to report how many sessions they had participated in, to rate the adequacy of the number of sessions, the appropriateness of the time for starting the GR, the extent of fulfilment of their expectations, and whether they would recommend the GR to a close friend in a similar situation. They were also asked if they would have appreciated the presence of a significant other in the group, and if there should have been a similar but separate group for significant others, or if a patient intervention was enough.
Patients were also asked to rate the perceived benefit of the GR on a four-step scale ("None at all"=0, ”Little”=1, ”Rather much”=2, ”Very much”=3) with respect to twelve areas: ”Challenging negative thoughts”, ”Distraction techniques”, ” Daily activity planning”, ”Problem solving”, ”Meeting other patients in the same situation”, ”Giving others support and help”, ”Getting support and help from other patients”, ”Physical activity”, ”Relaxation”, ”Breathing exercises”, ”Information by the dietician”, and ”Information by the physician”. In addition, they were asked to rate the perceived degree of difficulty in understanding the different parts of the GR on a four-step scale ("Very easy”=0, ”Rather easy”=1, ”Rather difficult”=2, ”Very difficult”=3) with respect to nine of the above mentioned areas. Some topics were considered inappropriate for the difficulty rating and were therefore excluded, i.e. ”Meeting other patients in the same situation”, ”Giving others support and help”, and ”Getting support and help from other patients”. One question concerned patients’ view of the GR group composition.

Demographic data were collected at inclusion on age, diagnosis, gender and residential area.

Medical background data

Data on disease stage and treatments were collected from the medical records at the surgical and oncological departments. Advanced disease was defined as locally advanced disease (T 3 or 4 before or after surgery), >7 positive axillary nodes and/or distant metastases for breast cancer, distant metastases for gastrointestinal cancers, and T-stage 4 disease, positive lymph node status (N+) and/or distant metastases for prostate cancers. Extensive treatment was defined as chemotherapy in addition to surgery and radiotherapy for breast cancer patients, chemotherapy in addition to surgery for gastrointestinal cancer patients, and prostatectomy or external radiotherapy combined with brachytherapy for prostate cancer patients.
Number of IPS contacts

Data on the number of sessions with the project psychologists were collected from patient files kept by the psychologists.

An overview of the questionnaires used is presented in Table 5.

Table 5. Overview of data collection instruments used in Studies I-IV

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>EORTC QLQ-C30</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>HADS</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>IES</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>InQ:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GQLI</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>ISSI</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Medical background data</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>MBSS</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Number of IPS contacts</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire on patient participation and satisfaction with the GR</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Statistical methods

Substitution of missing values on questionnaires scales (i.e. EORTC QLQ-C30, HADS, IES) was made if the patient had completed at least half of the items in a specific subscale. The missing value was replaced by the mean of completed items in that scale for each patient. If more than half of the scale items were incomplete, the scale score was treated as missing data. This accords with the procedure advocated in the EORTC manual (Fayers et al., 1997).

In Studies II and III, evaluating the potential effects of the Rehabilitation intervention, comparisons were made between patients’ randomised to Rehabilitation (ISGR+GR) and those randomised to no Rehabilitation, i.e. the Control group (IS+SC). This comparison was chosen rather than comparisons involving all four randomised groups in order to increase statistical power. Thus, IS was equally distributed between the Rehabilitation and Control
groups. Analyses have also been performed to explore the existence of interaction effects between Rehabilitation (GR+ISGR) / Control (IS+SC) and Individual Support (IS+ISGR) / Control (GR+SC) (i.e. a 2x2 table). There were no such interactions in the data from the instruments used in the present study (EORTC QLQ-C30, HADS, IES) (data to be published elsewhere).

There were no differences between ISGR and GR, nor between IS and SC concerning age, diagnosis, gender or those <65 vs ≥65 years (data not shown).

In analyses including age, patients were divided in groups of <65 years and ≥65 years. This represents the age of retirement in Sweden.

In Study I, Mann-Whitney U-tests were used for comparisons of participation rates, satisfaction, perceived benefit and perceived difficulty of the GR techniques between genders, age groups and between groups of patients offered only GR and those offered the ISGR combination. Kruskal-Wallis one-way analysis of variance by ranks was used for comparisons between diagnoses. The Chi2-test was employed to study if there were differences between patients who would have liked to have a significant other present in the GR group vs those who would not, and to elucidate the extent to which participation in the IS affected the need for later GR.

In Study II, repeated-measures ANCOVA was used to analyse the short- and long-term effects of Rehabilitation vs. Control on quality of life, anxiety, depression, intrusion and avoidance. The baseline assessment of each measure was used as a covariate. ANCOVA was used to increase the sensitivity of the test of main effects and interactions by reduction of
error terms (Tabachnick & Fidell, 1996). The Tukey-HSD test was employed for post hoc testing in case of significant interactions.

In Study III, two-way analyses of covariance (ANCOVA) were used to assess potential interactions between coping style (Monitoring/Blunting) and randomisation group (Rehabilitation/Control) with respect to anxiety, depression, intrusion and avoidance at the 3-month assessment. The baseline assessments were used as covariates. The Least Significant Difference (LSD) test was used for post hoc comparisons. Chi-2 tests were employed for assessment of the independence of coping style and anxiety and depression (in terms of HAD case/non-case status).

In Study IV, bivariate correlations were computed between the independent variables, using Pearson correlation coefficients, point-biserial coefficients and Phi2/Chi2 tests. Hierarchical regression analyses were performed to determine if information assessed at inclusion regarding diagnosis, disease stage, primary treatment, comorbidity, age, marital status, having children <18 years living at home, social integration, outside home activity level, well-being, and anxiety and depressive symptoms predicted aspects of quality of life (Physical Functioning, Emotional Functioning, Global Quality of Life) one year later. All models were adjusted for randomisation.

The STATISTICA 4.1 software package for Macintosh (StatSoft, Inc.) was used for all analyses.
RESULTS

Summaries of Studies I-IV

Study I

The aims were to describe patients’ degree of satisfaction with the GR, perceived benefits and perceived difficulty of the employed GR techniques. Participation rates, satisfaction, perceived benefit and difficulty were compared between diagnoses, genders, age groups and between groups of patients offered only GR and those offered ISGR.

Of the original 221 patients’ randomised to GR or the combination ISGR, 24 had decided to discontinue participation in the SCR-project before the time of invitation and one patient had died. Of the 196 patients who were invited, 132 (67%) participated in the GR programme. More patients randomised to ISGR (42/106) declined participation compared to patients randomised to GR only (22/90). Patients who had received ≥ 3 sessions of IPS participated to a larger extent than did patients who had received 1-2 sessions. About three fourths (76%, 98/129) of patients who lived in Uppsala municipality participated in the GR compared to half (51%, 34/67) of those living outside the municipality. Men and women participated to the same extent.

A total of 21 groups were conducted, each consisting of 3-9 patients (mean 6.0, sd 2.25). Eleven groups consisted of patients with breast (9 groups) or prostate cancer (2 groups), and 10 were mixed (8 prostate and GI, 2 breast and GI). Eighty percent (n=105) of the patients participated in five or more sessions. The questionnaire concerning patient participation and satisfaction with the GR was sent to all patients (n=132) who had accepted participation in the GR programme, and a total of 111 (84%) responded. Eighty percent of these had participated in five or more sessions. Most patients were satisfied with the number of sessions and thought
the start of the GR was appropriately timed. However, about 20% wanted more sessions. There was a significantly larger proportion of patients randomised to GR alone than to ISGR who wanted more sessions. About 20% of the patients had preferred an earlier start. Most of these were younger, breast cancer patients, and accordingly, women. Relaxation, physical training, encountering others in the same situation, breathing exercises, and the information provided by physician and dietician were experienced as the most beneficial. Women rated more benefit of relaxation than did men. Breast and prostate cancer patients rated more benefit of meeting others, physical exercise and of information by the physician than did GI cancer patients. Patient ratings of perceived benefit of components of the Group Rehabilitation programme are shown in Table 6. Most components of the GR programme were rated as very or rather easy to understand and apply. However, 27–35% perceived three types of coping skills (challenging automatic negative thoughts, distraction and problem solving) as rather or very difficult. Prostate cancer patients rated the information by the physician as more difficult than did breast and GI patients.

Most patients would (86%) or would maybe (10%) recommend GR to a friend in the same situation. More patients randomised to GR alone would recommend GR to a friend than those who had been offered the combination of IS and GR. Only four patients with GI cancer would probably not recommend GR to a friend.
Table 6. Patient ratings of perceived benefit of components of the Group Rehabilitation programme: Number of patients (%).

<table>
<thead>
<tr>
<th>Perceived benefit</th>
<th>None (n%)</th>
<th>Some (n%)</th>
<th>Rather much (n%)</th>
<th>Much (n%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging negative thoughts (n=109)</td>
<td>10 (9%)</td>
<td>30 (28%)</td>
<td>49 (45%)</td>
<td>20 (18%)</td>
</tr>
<tr>
<td>Distraction (n=108)</td>
<td>14 (13%)</td>
<td>33 (31%)</td>
<td>48 (44%)</td>
<td>13 (12%)</td>
</tr>
<tr>
<td>Daily planning (n=109)</td>
<td>19 (17%)</td>
<td>37 (34%)</td>
<td>39 (36%)</td>
<td>14 (13%)</td>
</tr>
<tr>
<td>Problem solving (n=108)</td>
<td>13 (12%)</td>
<td>28 (26%)</td>
<td>49 (45%)</td>
<td>18 (17%)</td>
</tr>
<tr>
<td>Physical training (n=110)</td>
<td>3 (3%)</td>
<td>9 (8%)</td>
<td>38 (35%)</td>
<td>60 (55%)</td>
</tr>
<tr>
<td>Relaxation (n=110)</td>
<td>3 (3%)</td>
<td>9 (8%)</td>
<td>25 (23%)</td>
<td>73 (66%)</td>
</tr>
<tr>
<td>Breathing exercises (n=108)</td>
<td>5 (5%)</td>
<td>13 (12%)</td>
<td>31 (29%)</td>
<td>59 (55%)</td>
</tr>
<tr>
<td>Dietetic information (n=96)</td>
<td>5 (5%)</td>
<td>19 (20%)</td>
<td>44 (46%)</td>
<td>28 (29%)</td>
</tr>
<tr>
<td>Medical information (n=103)</td>
<td>4 (4%)</td>
<td>18 (17%)</td>
<td>35 (34%)</td>
<td>46 (45%)</td>
</tr>
<tr>
<td>Encountering others in the same situation (n=110)</td>
<td>3 (3%)</td>
<td>13 (12%)</td>
<td>35 (32%)</td>
<td>59 (54%)</td>
</tr>
<tr>
<td>Giving others support and help* (n=93)</td>
<td>10 (11%)</td>
<td>34 (37%)</td>
<td>30 (32%)</td>
<td>19 (20%)</td>
</tr>
<tr>
<td>Getting support and help from others* (n=94)</td>
<td>10 (11%)</td>
<td>30 (32%)</td>
<td>32 (34%)</td>
<td>22 (23%)</td>
</tr>
</tbody>
</table>

* these questions were added after four groups

Most patients did not want a significant other to be present at the GR sessions. Of those who had wanted a significant other to be present, a significantly larger proportion were men rather than women. Half of the patients would have liked a separate group for significant others. Most patients found the group composition to be adequate, even if some had liked the group to be more homogenous or had wanted more group members.

In summary, most patients were satisfied with the number of sessions and the timing of the start of the GR. Relaxation, physical training, encountering others in the same situation, breathing exercises, and the informative parts (physician, dietician) were perceived as the most beneficial. Most components of the GR programme were rated as very or rather easy, but some patients perceived three types of coping skills as rather or very difficult. Most patients would recommend GR to a friend in the same situation.
Study II

The aims were to evaluate the short- and long-term effects of the GR programme on quality of life (EORTC QLQ-C30), anxiety, depression (HADS), and intrusion and avoidance (IES) in newly diagnosed breast, gastrointestinal and prostate cancer patients. The study is based on the assessments performed 3 months after randomisation in the SCR project (baseline in the present study), and 3, 9 and 21 months later. The short-term follow-up consists of the assessments at 3 and 9 months, and the long-term follow-up of the 21-month assessment.

Comparisons were made between patients offered GR (Rehabilitation, i.e. GR and ISGR) and those not offered GR (Control, i.e. IS and SC).

Forty-nine patients discontinued the SCR project between inclusion and the baseline assessment. The most common reasons for discontinuing were “not interested” (n=17), “too many/difficult questions” (n=16) and “too much” (n=8). Four patients had died. An additional 49 patients discontinued participation during the follow-up period. Of these, 29 had died and 20 declined further participation.

Overall, patients had high scores on the functional scales and low scores on symptom scales and items in the EORTC QLQ-C30 (i.e. quality of life). Also, they had low scores on anxiety, depression, intrusion and avoidance.

At the short-term follow-up, there were significant differences between the randomisation groups for the Physical Functioning scale [F (1,345)=6.27, p<0.05] and Appetite Loss [F (1,346)=4.00, p<0.05]. The Rehabilitation group had higher overall scores on Physical Functioning than the Control group, but the post-hoc tests failed to reveal any significant between-groups differences. The Rehabilitation group had a higher score than Controls for
Appetite Loss at the 9-month assessment (mean 6.6, sd. 17.2 vs mean 2.8, sd. 12.7) (Tukey HSD). Role [F (1,344)=7.45, p<0.01] and Social Functioning scores [F (1,347)=5.55, p<0.05] increased significantly over time, and there was also a significant reduction for the Fatigue scale [F (1,345)=9.77, p<0.01]. For the Role Function scale, there was a significant randomisation by time interaction [F (1,344)=7.45, p<0.01]. The Rehabilitation group increased significantly from the 3-month to the 9-month assessment (mean 81.8, sd. 29.1 to mean 89.7, sd. 23.6), while the Control group remained at the baseline level (mean 86.4, sd 25.3 to mean 86.4, sd. 25.3) (Tukey HSD). There was also a significant randomisation by time interaction for Appetite Loss [F (1,347)=5.58, p<0.05], which decreased over time in the Control group, and increased in the Rehabilitation group (mean 4.0, sd. 12.4 to mean 2.8, sd. 12.7 vs. mean 3.7, sd. 11.1 to mean 6.6, sd. 17.2) (Tukey HSD). At the short-term follow-up, there were no main effects of randomisation or time, nor any significant randomisation by time interactions for anxiety, depression, intrusion or avoidance.

At the long-term follow-up, there were no differences between the Rehabilitation and Control groups for quality of life, depression, intrusion or avoidance. However, the Rehabilitation group had significantly lower anxiety scores than the Control group at the 21-month assessment (mean 3.0, sd. 3.4 vs. mean 3.5, sd. 3.8) [F (1,329)=5.70, p<0.05] (Tukey HSD).

In summary, the GR programme had limited positive short-term effects on Role Function, and a long-term effect on anxiety. It should be noted that the patients had overall high scores on functional scales and reported very few symptoms or symptoms of mainly low intensity. Thus, major improvements on the outcome measures are unrealistic to expect. In view of the large number of statistical comparisons, the results should be interpreted with caution. It
should be noted that the present interventions were offered to all patients with no previous screening.

**Study III**

The major aim was to investigate the extent to which the Miller Behavioural Style Scale (MBSS) (Monitors vs. Blunters) could be used to differentiate cancer patients (breast, gastrointestinal, prostate) who are likely to benefit from rehabilitation efforts with a strong information component from those who are not. Specific aims were to assess: the proportion of cancer patients with Monitoring or Blunting coping styles at inclusion; the levels of anxiety, depression, and subjective distress in these subgroups at baseline and at the 3-month assessment; and possible interactions between coping style (Monitoring/Blunting), and group assignment (Rehabilitation/Control) with respect to anxiety, depression and subjective distress.

A total of 368 (83% of 442) patients completed the MBSS at inclusion. Eighteen patients declined further participation after the assessment at inclusion. Baseline or 3-month assessment were missing for 18 patients, 4 declined further participation after the baseline assessment, and 3 patients died. Thus, 325 (88% of 368) were included in Study III.

Patients who did not complete the MBSS were older (mean 69.9, sd 11.9 vs. mean 62.3, sd 13.0) (t=4.62, df=440, p<0.001), and more men (40/181) than women (34/261) did not complete the questions (Chi2=6.31, df=1, p<0.05).
Using the sum score, 210 patients were categorised as Monitors and 158 as Blunters. There were no differences between these groups with respect to diagnosis, gender, number of patients below or above 65 years, marital status, education, or randomisation groups.

There were no statistically significant main effects of coping style (Monitors/Blunters) or randomisation groups (Rehabilitation/Control) or their interactions with respect to anxiety or depression. Likewise, there were no main effects for intrusion or avoidance. However, significant interactions of coping style by randomisation groups were found with respect to avoidance among patients with breast cancer \[F (1,175) = 5.94, p<0.05\] and those with prostate cancer \[F (1,70) = 7.19, p<0.01\]. For patients with breast cancer, Monitors in the Rehabilitation group had higher avoidance scores at the 3-month assessment than did Control Monitors (mean 11.98, sd. 8.75 vs. mean 8.33, sd. 8.31), whereas there were no differences between the Blunter groups (mean 10.06, sd. 7.87. vs. mean 10.34, sd. 9.54) (LSD test).

Among patients with prostate cancer, Blunters in the Rehabilitation group had higher scores at the 3-month assessment than did Blunters in the Control group (mean 13.41, sd. 10.49 vs. mean 7.50, sd. 6.18) (LSD test). The reverse tendency was observed for Monitors but it did not reach statistical significance (mean 8.21, sd. 7.32 vs. mean 12.14, sd. 8.08).

To further analyse these response patterns, additional ANCOVAs were performed. These analyses were performed for Monitors and Blunters separately and concerned interactions between diagnosis (breast/prostate) and randomisation (Rehabilitation/Control). Significant interactions were found only among Monitors. Prostate cancer patients in the Rehabilitation group reported less anxiety and depression at the 3-month assessment than did those in the Control group (anxiety mean 2.26, sd. 2.90 vs. mean 5.41, sd. 4.63); (depression mean 2.84, sd. 3.67 vs. mean 4.41, sd. 4.72) (LSD test). Anxiety and depression levels were not related to
randomisation for the breast cancer patients. Likewise, for intrusion and avoidance, prostate cancer patients in the Rehabilitation group reported lower problem levels than did those in the Control group (intrusion mean 4.53, sd. 5.24 vs. mean 8.75, sd. 7.11); (avoidance mean 8.21, sd. 7.32 vs. mean 12.14, sd. 8.08) (LSD test). In contrast, breast cancer patients in the Control group improved but there was no change in the Rehabilitation group (LSD test). Table 7 shows mean values and sd of HADS anxiety and depression, IES intrusion and avoidance among breast and prostate cancer Monitors in the Rehabilitation and Control groups.

Table 7. Mean values (sd) of HADS anxiety and depression, IES intrusion and avoidance among breast or prostate cancer Monitors in the Rehabilitation and Control groups after Rehabilitation. Preintervention measures were used as the covariates.

<table>
<thead>
<tr>
<th>MONITORS</th>
<th>HADS anxiety</th>
<th>HADS depression</th>
<th>IES intrusion</th>
<th>IES avoidance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breast</td>
<td>Prostate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rehabilitation n=58</td>
<td>Control n=48</td>
<td>Rehabilitation n=19</td>
<td>Control n=22</td>
</tr>
<tr>
<td>pre</td>
<td>4.26 (4.09)</td>
<td>3.75 (4.04)</td>
<td>2.84 (2.85)</td>
<td>2.26 (2.90)</td>
</tr>
<tr>
<td>post</td>
<td>4.24 (3.61)</td>
<td>3.79 (3.88)</td>
<td>2.26 (4.63)</td>
<td>5.41 (4.63)</td>
</tr>
<tr>
<td></td>
<td>Breast</td>
<td>Prostate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rehabilitation n=19</td>
<td>Control n=22</td>
<td>Rehabilitation n=19</td>
<td>Control n=22</td>
</tr>
<tr>
<td>pre</td>
<td>2.33 (2.42)</td>
<td>2.86 (3.40)</td>
<td>3.53 (3.88)</td>
<td>3.45 (3.83)</td>
</tr>
<tr>
<td>post</td>
<td>2.59 (2.60)</td>
<td>2.88 (3.32)</td>
<td>2.84 (3.67)</td>
<td>4.41 (4.72)</td>
</tr>
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<td></td>
<td>n=58</td>
<td>n=49</td>
<td>n=19</td>
<td>n=21</td>
</tr>
<tr>
<td>pre</td>
<td>10.69 (7.84)</td>
<td>9.51 (6.99)</td>
<td>5.37 (5.87)</td>
<td>8.33 (6.67)</td>
</tr>
<tr>
<td>post</td>
<td>10.14 (6.93)</td>
<td>7.86 (7.33)</td>
<td>4.53 (5.24)</td>
<td>8.75 (7.11)</td>
</tr>
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<td></td>
<td>n=58</td>
<td>n=49</td>
<td>n=19</td>
<td>n=21</td>
</tr>
<tr>
<td>pre</td>
<td>11.71 (8.74)</td>
<td>10.29 (9.54)</td>
<td>9.79 (7.69)</td>
<td>8.95 (5.89)</td>
</tr>
<tr>
<td>post</td>
<td>11.98 (8.75)</td>
<td>8.33 (8.31)</td>
<td>8.21 (7.32)</td>
<td>12.14 (8.08)</td>
</tr>
</tbody>
</table>

Underlined values indicate differences between diagnostic groups. Bold values indicate differences within (diagnostic groups) between Rehabilitation and Control.

Additional ANCOVAs were performed of age (<65 years and ≥65 years) by randomisation interactions for breast and prostate cancer patients separately, since breast cancer patients were younger than prostate cancer patients (mean 57.4, sd. 13.4 vs. mean 70.8, sd.7.4)
(t=10.06, df=339, p<0.001). There were no significant interactions or main effects on anxiety, depression, intrusion or avoidance.

The extent to which patients could be unequivocally classified as Monitors or Blunters on the basis of subscale data was explored by dividing them in high and low Monitors and Blunters. Approximately one fourth of the patients was classified in each of the four possible categories: low monitor/low blunter (n=98, 27%), high monitor/low blunter (n=94, 26%), low monitor/high blunter (n=70, 19%) and high monitor/high blunter (n=106, 29%). There were no significant differences between these groups with respect to diagnosis, gender, or randomisation groups. More patients ≥65 years were categorised as high monitor/high blunter (62/180, 34%) rather than low monitor/high blunter (26/180, 14%) (Chi2=9.21, df=3, p<0.05). Patients <65 years were almost equally distributed between the four categories.

In summary, the results suggest that only the Monitor concept was useful for distinguishing cancer patients who are likely to benefit from rehabilitation with a strong information component from those who are not. The participation in the Rehabilitation intervention did not have any effect on anxiety, depression, intrusion and avoidance among Blunters. For prostate cancer Monitors, Rehabilitation reduced anxiety, depression, intrusion and avoidance while this was not true for breast cancer Monitors. For the latter, intrusion and avoidance were reduced in the Control group. It may be that the timing of the intervention is of great importance for these diagnostic groups. The Rehabilitation programme started about four months after randomisation, which was before the initiation of medical treatment for many prostate cancer patients. The breast cancer patients were undergoing or had terminated their treatment.
Study IV

The aim was to explore to what extent quality of life [i.e. the subscales Physical Functioning (PF), Emotional Functioning (EF) and global Quality of Life (QoL) from the EORTC QLQ-C30] one year after inclusion in the SCR project among patients with breast, gastrointestinal or prostate cancer could be predicted by patients’ medical status, socio-demographic status, Outside Home Activity Level, general satisfaction with life and emotional problems in conjunction with diagnosis (in the present study, inclusion).

Data on medical variables (i.e. diagnosis, disease stage, primary treatment and comorbidity) that are usually available at or in conjunction with diagnosis were included first in the hierarchical regression analyses. After that, easily attainable information on demographic factors (age, marital status and children at home) was added. In the final steps, questionnaire data were added concerning social support, Outside Home Activity Level, well-being and anxiety and depressive symptoms. Randomisation was added first in each of the hierarchical regression analyses in order to reduce possible confounding influence of this variable.

At the assessment one year after inclusion, 380 (79%) of the 481 patients were still in the study. Fifty-six patients (12%) had discontinued participation. Of these, 20 were breast, 18 gastrointestinal and 18 prostate cancer patients. Forty-five (9%) patients (n=3 breast, n=37 gastrointestinal, n=5 prostate) had died.

In the final model, advanced disease, having one or more comorbid conditions and higher age was associated with a lower PF one year after inclusion. Also, a high Outside Home Activity Level and high self-rated well-being were predictive of a better PF. The final model explained 22% of the total variance in PF.
In the final model for EF, a high self-rated well-being was associated with a better EF one year after inclusion. Being classified as a HADS case (≥8 on either or both of the subscales) was associated with a reduced EF. The final model explained 24% of the total variance in EF.

Having one or more comorbid conditions was associated with a lower QoL one year after inclusion. Self-rated well-being was associated with a higher QoL. The final model explained 24% of the total variance in QoL.

Self-rated well-being was a significant predictor in all models. This scale consists of the subscales Social, Physical and Mental well-being. New models for prediction of PF, EF and Global QoL were constructed using the subscales in place of the total scale. Physical well-being was the only subscale that made a significant contribution for PF (β=0.30, p<0.001) and QoL (β=0.24, p<0.001). For EF, Mental well-being was the only subscale to prove significant (β=0.22, p<0.001). The patterns of other significant predictors were the same as in the original analyses.

Levels of PF, EF and global QoL were high one year after inclusion. For many patients, quality of life had returned to normal levels one year after their cancer diagnosis. The levels of PF and QoL for the breast cancer patients are comparable to the reference values for women in a sample of the Swedish general population reported by Michelson et al. (2000). Men with prostate cancer had a somewhat lower level than men in the Swedish reference sample. The present patients had a somewhat higher score for EF one year after inclusion than did the reference sample.
In summary, the linear regression models explained 22 to 24% of the variance in PF, EF and global QoL. The results indicate that the long-term quality of life of cancer patients can be predicted, at least partly, by information available in conjunction with diagnosis. Low PF was associated with having an advanced disease, comorbid conditions, high age, a low Outside Home Activity Level, and a low self-rated physical well-being at diagnosis. Lower EF was associated with lower mental well-being and psychological problems at diagnosis. Lower global QoL was associated with extensive treatment, comorbid conditions and lower physical well-being at diagnosis.
DISCUSSION

General discussion
To our knowledge, the SCR-project is one of the largest randomised studies of the effects of psychosocial interventions for a heterogenous group of cancer patients conducted to date. The results show that many patients had high overall functioning and low levels of symptoms, and that many of these problems decreased over time (Hellbom et al., submitted and Study II). The levels of HRQOL one year after diagnosis were almost comparable to the reference values reported for a sample of the Swedish general population (Michelson et al., 2000). The group rehabilitation intervention was appreciated by the patients (Study I), but there is very limited evidence that the intervention improved patient conditions beyond that of standard care. The only evidence of positive overall effects were single findings concerning role function and anxiety (Study II). However, prostate cancer patients classified as Monitors appeared to profit from the GR programme (Study III). Taken together, the findings suggest that offers of rehabilitation should be directed to selected subgroups of patients. Similar conclusions have been reached for the individual psychological support, that consisted another part of the SCR project (Hellbom, 2001).

Satisfaction with group rehabilitation, perceived benefits and difficulty of techniques
Surveys of patient satisfaction with care tend to yield positive results, possibly reflecting social desirability (Ley, 1988) to a large extent. Earlier studies of psychosocial group interventions for cancer patients (Bottomley, 1998; Gregoire et al., 1997; Heinrich & Schag, 1985; Telch & Telch, 1986; Watson et al., 1996) have shown that, in general, patients were satisfied when asked to give an overall assessment of the intervention. However, when asked about separate components of interventions, ratings tend to vary. In Study I, a substantial proportion of patients stated that they experienced benefits by participation in the GR and
rated most of its components as “very easy” or “rather easy” to learn. There were variations in patient benefit ratings of the perceived benefit of the several components of the GR programme. This suggests that the satisfaction ratings were not strongly or equally affected by social desirability.

It seems that most patients perceived benefit from the physical exercise component. This exercise was adapted to patients’ physical capacity and they were encouraged to take rest periods during the sessions if needed. The information by the physician and the dietician was also appreciated. The group situation provided an opportunity for patients to ask questions and those who were reluctant to raise issues or had difficulty articulating their concerns, may have been encouraged by finding that others raised similar questions. About thirty percent of participants perceived three types of coping skills (challenging automatic negative thoughts, distraction and problem solving) as rather or very difficult to understand. It may be that the number of sessions was not sufficient for teaching CBT in a group setting. Most patients were satisfied with the number of sessions and the timing of the start of the GR. This indicates that the format of the GR programme was well suited for a majority. In sum, it seems that most patients perceived benefits from the physical and informative parts of the programme. The assessment of benefits of the CBT components may have been performed too early after group termination. Most of these techniques have a general applicability and the intention was that patients should use these when problems occurred.

**Participation, satisfaction, perceived benefits and difficulty of techniques: Group differences**

Sixty percent of the randomised patients participated. This is a high participation rate since the SCR-project recruited all newly diagnosed patients without screening for psychosocial or other needs. In several other studies (e.g. Antoni et al., 2001; Cunningham et al., 1995;
Edelman et al., 1999b; Watson et al., 1996), patients were recruited after asking for psychosocial support or replying to media advertising, i.e. through self-referral. Men and women participated to the same extent. Earlier studies (e.g Berglund et al., 1993; Gray et al., 1996; Taylor et al., 1986) have found that men have a strong interest in information about disease and treatment but are less likely than women to participate in support/rehabilitation groups. One explanation may be that when patients were informed about the GR at inclusion, the educational aspects were stressed. This may have been attractive to men. There were no differences in participation rates between groups with different diagnoses, but more older compared to younger breast cancer women declined participation. More patients (76%) who lived in Uppsala municipality participated in the GR compared to those living outside the municipality (50%). This difference raises the question of the accessibility of the GR. For some patients, the travels took several hours, and the GR was held during daytime. For some patients, e.g. those working, it would probably be better if it could be offered in the evening or as a more concentrated weekend course. The latter alternative has been shown to be almost as effective as weekly sessions (Cunningham et al., 1995).

There were few differences between diagnoses and genders, and none between age groups with regard to perceived benefits and difficulty of the GR techniques. This suggests that the GR programme is easy to understand and apply. Also, the content of the programme was of a general nature which may have contributed to the few group differences. Another explanation may be that the instrument used for evaluation of patient participation and satisfaction with the GR is not sensitive enough to detect group differences. This instrument was developed explicitly for the present study and its validity and reliability have not been established. No differences were found between groups of patients offered only GR or the combination of ISGR. The basis for expecting such differences is that those offered the combination had had
more opportunities to learn and practice CBT which was included also in the Individual Psychological Support (IPS). However, the IPS component of the IS was problem-focused, and the patients were therefore only taught skills to the extent that they needed these at the present time (Hellbom et al., 1998).

Patients who had received $\geq 3$ sessions of IPS participated to a larger extent in the GR than did patients who had received 1-2 such sessions. A possible explanation of this may be that the IPS and the GR attracted those in most need of psychological support. Partial support for this explanation is provided by the observation that patients who had fewer problems, also had a smaller number of sessions of IPS than those with more problems (Hellbom et al., 1998). In a study of factors associated with cancer patients’ participation in support groups, Bauman et al. (1992) found that those who had consulted a psychiatrist, a psychologist, or other therapist were more likely to attend support groups meetings than were those who had not.

Breast and prostate cancer patients rated more benefits of meeting others and of information by the physician than did GI cancer patients. More homogenous groups may have led to higher ratings of perceived benefits also among the GI cancer patients. The original intention was to form diagnosis-specific groups. This was not always possible in order not to keep patients waiting for group start. There were few GI cancer patients, and in some groups there were only one or two with that type of diagnosis together with breast or prostate cancer patients. They may have felt that information about cancer and treatment was not sufficiently directed to them. Some patients with prostate cancer perceived the physician information as difficult. One explanation may be that information about breast and GI cancer is more standardised compared to information about prostate cancer which is more complex due to the
fact that there are several options for treatment and little consensus about priorities. However, it can not be ruled out that individual physicians have different abilities to provide information.

**Short- and long-term overall effects of group rehabilitation on quality of life, anxiety, depression, intrusion and avoidance**

There were no short-term effects of the rehabilitation programme on anxiety, depression, intrusion or avoidance. A single finding was that the Rehabilitation group increased significantly more from the 3 to the 9 month follow-up on the EORTC QLQ-C30 Role Function scale than did the Control group. At the 21-month follow-up, there were no differences between the Rehabilitation and Control groups with respect to quality of life, depression, intrusion or avoidance. However, the Rehabilitation group had significantly lower anxiety scores than the Control group. Thus, the effects of the GR intervention were small or non-existent. The few statistically significant findings should be interpreted with caution due to the large number of analyses.

It should be noted that the quality of life ratings were high and that levels of symptoms, anxiety, depression, intrusion and avoidance at the 3 month assessment were low in this unscreened, heterogenous sample of cancer patients. Therefore, improvements of quality of life and functions were hard to demonstrate. The same is true for anxiety, depression, intrusion, avoidance and symptoms. Patients were included in the present study on the basis of cancer diagnoses, not the presence of psychological problems. Thus, only a small number of patients were actual “cases”. Hellbom et al. (submitted) found no effects of the IPS on quality of life, anxiety, depression, intrusion or avoidance between diagnosis and a 3 month follow-up in analyses that where performed on the same sample as in Study II, not even after
Zabora et al. (2001) argue that administration of an intervention in a general population of cancer patients may produce artificially positive results, because many of the patients will adapt to their cancer diagnosis without any clinical intervention. Also, it has been demonstrated earlier that unscreened groups of cancer patients go through a period of relatively rapid improvement after diagnosis and medical treatment (Nordin & Glimelius, 1997; 1998). Earlier studies within the SCR-project have shown that scores on several quality of life and distress scales improved substantially over time for all patients, independent of randomisation (Hellbom et al., submitted and Study II). Thus, such improvement processes may also have contributed to the difficulties to demonstrate effects of the GR intervention.

Ross et al. (2002) recently found support for the hypothesis that only cancer patients with severe psychological distress are likely to benefit from psychosocial intervention. In their review, significant effects on anxiety and/or depression were found in studies that included only patients who were suffering from psychological distress according to a screening procedure (Evans & Connis, 1995; Greer et al., 1992; Mantovani et al., 1996; Telch & Telch, 1986). Thus, the fact that no screening was attempted in the present study is likely to have made the demonstration of effects difficult. However, if we had screened for anxiety or depression using ≥8 on the HADS as a cut-off at inclusion (diagnosis), only 30 percent of eligible patients (125/415) would have been randomised. If we had used the scores of the 3
month assessment (baseline for Studies II and III) for screening, only 22 % (85/386) had been randomised. This would have resulted in a very weak statistical power due to the small number of patients per group. Also, it would have become difficult to form rehabilitation groups within reasonable time periods leaving many patients to wait long before the rehabilitation started. This had not been a feasible procedure. Also, even if screened for anxiety and depression, patients may chose not to accept offered treatment. Ford et al. (1990) offered group psychotherapy to 39 cancer patients with moderate anxiety and/or depression identified by HADS, and only 10 consented to participate.

A meta-analysis by van’t Spijker et al. (1997) found that the proportions of patients with depression, anxiety, and general psychological distress reported in studies before 1988 were significantly larger than corresponding values reported in later studies. Reasons for this may be improvements in medical treatment, earlier diagnosis leading to a better prognosis, better patient information and education, and improved patient care. One example of improved treatment is the introduction of selective 5-HT3-receptor inhibitors, which have led to more patients being treated with chemotherapy without fear of intense nausea and vomiting. Such improvements may have contributed to the low overall levels of problems in the present study and made it more difficult to demonstrate effects of the GR intervention. Also, earlier psychosocial research projects performed in Uppsala county (Glimelius et al., 1995) and the extensive education of medical staff prior to and during the SCR-project (Johansson et al., 1999) may have resulted in an increased awareness among all staff of the importance of the psychosocial aspects of cancer care.

Longer follow-up periods than 6 months are rare in evaluations of cancer rehabilitation, except for those evaluating survival (Edelman et al., 1999b; Fawzy et al., 1993; Spiegel et al.,
Thus, it is difficult to find other studies, with which to compare the present 9- and 21-month follow-up findings. However, in their 3-year follow-up of an 8-week educational intervention, Helgeson et al. (2001) found that patients offered the intervention had higher levels of vitality, lower levels of bodily pain, and higher levels of physical functioning compared to controls, although all of the effects were small and dissipated over time. These authors suggested that the long-term effects may be due to the fact that women receiving the intervention had been provided with information (i.e. on nutrition and exercise) that they were able to use to in their daily lives. Simpson et al. (2001) have shown that women with breast cancer who had participated in a 6-week psychosocial intervention had less depression, less mood disturbance, fewer psychiatric symptoms, and better quality of life than controls at postintervention and at 2-year follow-up. Interestingly, there were no such effects at the 1-year follow-up. Thus, there is very little compelling evidence of effects of psychosocial interventions at follow-ups performed after 12 months.

Identification of subgroups likely to benefit from rehabilitation: The Monitor/Blunter distinction

There were no main differences between Monitors and Blunters with respect to anxiety, depression, intrusion or avoidance. The participation in the Rehabilitation intervention did not have any effect on anxiety, depression, intrusion and avoidance among Blunters. Only the Monitor concept was useful for distinguishing a subgroup of cancer patients who benefited from the GR programme. Thus, the GR programme reduced anxiety, depression, intrusion and avoidance for prostate cancer Monitors between 3- (baseline) and 6-month assessments. It might be that prostate cancer Monitors found the information given and the possibility to discuss their situation to be important to them. Many of the patients were still in the process of determination of a diagnosis and medical treatment not had been initiated.
Among breast cancer patients, intrusion and avoidance were reduced from 3- to 6-month assessment for Monitors in the Control group, but not in the Rehabilitation group. Lampic and co-workers (Lampic et al., 1994) have shown that many cancer survivors worry about suffering a recurrence and about developing a secondary cancer. Many of the breast cancer Monitors had terminated their treatment and for those in the Rehabilitation group, the information given may have raised questions about the future and of possible recurrence of the disease. It may be that the timing of the intervention is of great importance for these diagnostic groups. Breast and prostate cancer patients were in different phases of their disease and treatment. The optimal timing of an intervention is an issue that is seldomly discussed. In a study of newly diagnosed patients with different types of cancer by Edgar et al. (1992), the same intervention was provided immediately after the diagnosis or 4 months later. The group that received the intervention later was significantly less depressed, anxious and worried 8 months after inclusion, and continued to be less worried about their illness than the group given the intervention early. Patients with other diagnoses than breast cancer appeared to benefit most from the late intervention. In the present study, most of the patients who stated that the intervention was offered too late were breast cancer patients (Study I). It might be that many breast cancer patients need the intervention earlier than after 3-4 months.

The failure to reduce anxiety, depression, intrusion and avoidance among breast cancer Monitors in the Rehabilitation group (Study III) may also be given another interpretation. It is possible that in the group setting, patients perceive many statements by their co-patients as potentially threatening. If so, such statements may only partly be handled in the group setting. Threatening thoughts may thus maintain subjective distress and the CBT component of the intervention may have been insufficient in length to teach cognitive-behavioural techniques properly. Helgeson et al. (1999) found a similar surprising result in their study comparing
educational and peer discussion groups. They had expected that peer discussion should lead to downward comparisons, i.e. feeling lucky when patients compared themselves with those worse-off. Instead, women reported feeling anxious and concerned about their own condition when they faced worse-off others. In the educational group, where patients had no chance to discuss with each other, there was no such effect.

Prediction of quality of life aspects one year after diagnosis

Study IV explored the extent to which patients’ medical status, socio-demographic status, level of outside home activity, emotional problems, and general satisfaction with life at diagnosis can be used to predict aspects of quality of life (i.e. PF, EF, and QoL) one year later. The linear regression models explained 22-24 % of the variance in these aspects. The strategy was to choose predictor variables about which information is easily attainable for the health care professional. As mentioned earlier, levels of PF, EF and QoL were high one year after diagnosis, suggesting that quality of life had recovered for most patients. In agreement with earlier studies (Ramsey et al., 2000; Shimozuma et al., 1999; Ulander et al., 1997), the presence of advanced disease predicted a reduced physical function. Having one or more comorbid conditions predicted lower PF and QoL, which seems reasonable. A cancer diagnosis and its treatment add difficulties to those that patients already have due to other diseases. High age also predicted PF one year later, meaning that older patients had lower PF than younger patients.

The well-being scale was found to be a better predictor of PF, EF and QoL in all the multiple linear regression models than were many of the medical and demographic variables (Study IV). It is possible that patients’ perceptions of their degree of satisfaction with well-being
(social, physical, mental) is more important than are medical and socio-demographic factors for determining HRQOL.

PF and QoL could, at least partly, be predicted by medical and demographic variables. However, none of these predicted EF. EF was predicted only by lower mental well-being and being classified as a case on the basis of the HADS. This means that information about medical and demographic variables is not useful for identifying those in need of psychosocial interventions.

The workload of doctors and nurses limits their possibilities to identify patients in need of support (Razavi et al., 1990). Only a few patients ask for such support themselves. In Study IV, an attempt was made to identify factors in conjunction with the cancer diagnosis that are predictive of quality of life aspects one year later. The results suggest some variables that could be used to improve the early identification of patients in need of later rehabilitative efforts. Thus, older patients with advanced disease and other comorbid conditions who have few outside home activities may be the group in most need of physical rehabilitation. Attention should also be paid to patients with extensive treatment and comorbid conditions who rate their physical well-being low since this may affect their future quality of life. In order to identify patients in need of intervention to improve emotional functioning, assessment e.g. with the HADS will be needed.

Concluding comments
Sheard and Maguire (1999) have concluded that there are now adequate estimates of the overall magnitude of effect of psychological interventions on anxiety and depression in oncology. These authors suggested that future research should be directed at the following
specific questions: 1. the effectiveness of interventions targeted at those at risk of, or suffering significant distress; 2. the viability and effectiveness of group therapy in European oncology settings; 3. whether the large effects associated with group psycho-educational courses can be replicated; 4. whether positive effects are maintained at long-term follow-up.

The present study includes attempts to improve the empirical basis for the latter three questions. At the time when the SCR-project was planned, the issue of screening patients for significant distress before inclusion had not yet been seriously raised. The assumption then was that many patients would probably not benefit from psychosocial interventions but that there were no reliable measures for selecting those patients who were the most likely to do so. It was thus decided to offer group rehabilitation (and the individual interventions) to all patients. Many patients were also interested in participating in the Group Rehabilitation programme. Thus, the question of the feasibility of the group format can be answered affirmatively. Patients perceived benefits of different components of the programme. The physical and informative components were rated somewhat more beneficial than the CBT component. Meeting others in the same situation was also rated as beneficial. However, there were only small overall effects on quality of life and anxiety. These should be interpreted with caution due to the many analyses performed.

Methodological considerations
The original aim of the SCR project was to evaluate the effects of Individual Support (IS), Group Rehabilitation (GR) and their combination beyond that of standard care. Thus, the design was of a 2x2 nature. Preliminary analyses were performed to explore the existence of interactions between Rehabilitation/No Rehabilitation and Individual Support/No Individual Support (data not illustrated). There were no such interactions. This motivated the decision to
collapse the GR and ISGR groups to a GR condition which was compared to the IS plus SC group, combined to a Control condition in the present analyses (Studies II and III). These combinations were performed to increase the statistical power of the analyses.

More men than women declined participation in the SCR project, but those men who accepted participated to the same extent in the GR programme as did women (Study I). This is in line with the results by Krizek et al. (1999) who found that even if men with prostate cancer were less likely than breast cancer women to join support groups, once they did, they stayed in the groups to the same extent. However, it should be remembered that only a selected proportion of prostate cancer patients were invited to the SCR project. Those who participated in the SPCG IV study (Steineck et al., 2002), i.e. patients with localised disease, could not be invited since the SCR project was judged to be a potential threat to the integrity of the quality of life measurements of the SPCG IV. Thus, prostate cancer patients included in the SCR project were older and more of them had a more severe disease than is true for men with prostate cancer included in many other studies.

The patients in the present sample had EORTC QLQ-C30 scores comparable with those of a sample of the Swedish general population (Michelson et al., 2000). This made it difficult to demonstrate improvements due to the intervention, i.e. there were floor/ceiling effects. Simpson et al. (2002) also found that newly diagnosed breast cancer patients had good overall functioning and minimal symptoms one at one year follow-up. Thus, this is not an uncommon finding. Another possible reason for lack of significant differences in intervention studies lies in the psychometric characteristics of the assessment instruments. It is conceivable that lack of sensitivity to changes over time may have contributed to the lack of demonstrable effects.
However, the fact that a number of measures showed significant changes between assessments speaks against this explanation (Hellbom et al., submitted and Study II).

It is interesting to note that patient satisfaction with and perceived benefits of the intervention were high although the interventions had no or very little demonstrable effects on quality of life, anxiety, depression, intrusion or avoidance (Studies I and II). The questionnaire used to evaluate patient satisfaction was completed by 84% of those who had participated in the GR. This is a high response rate, why the data should be representative of those who participated in the GR. However, this questionnaire was mailed only to patients who had participated. This means that of the original sample of patients randomised to GR or ISGR, satisfaction data are available for only about 50%. This means that outcome data (Studies II, III) are available for a larger group of patients than that providing the data on satisfaction and perceived benefits (Study I). This may have contributed to the positive satisfaction/benefit findings, particularly since a majority (96%) of those who completed the questionnaire had participated in more than 3 GR sessions. They may constitute a self-selected sample with a positive attribute towards the GR programme.

Intention-to-treat analyses were employed in Studies II and III, meaning that all patients who were randomised to the respective condition and who had completed the questionnaires were retained in the analyses regardless of group attendance. There were no significant differences concerning anxiety and depression at any time point between those randomised patients who participated in the GR programme at least one session and those declining participation (data not shown). However, t-tests revealed that those who had participated had significantly higher mean values for intrusion and avoidance at the baseline, and the 3- and 9-month follow-up, compared with those who had not participated. Additional analyses were performed of
intrusion and avoidance data including only those who had attended at least one GR session. There were no significant differences between the Rehabilitation and Control conditions in these analyses.

Another possible reason for the lack of effects of the GR programme on quality of life, anxiety, depression, intrusion and avoidance may be that the group leaders did not have enough education and experience. However the psychologist who supervised the psychologists and nurses who acted as group leaders had extensive experience of rehabilitation groups for cancer patients. Remaining group leaders had more limited experience of group leadership. However, the pre-doctoral psychologists had education in CBT and had also participated in the education of GPs and home care nurses (Johansson et al., 1999) which was developed exclusively for the SCR project. The physicians, nurses, physiotherapist, and the dietician all had extensive experience of cancer care. Thus, the group leaders for each of the 21 groups appear to have been sufficiently prepared for conducting groups. Also, the GR programme was highly structured, which should have facilitated compliance among the group leaders.

The MBSS was found to be partly useful for differentiating cancer patients who are likely to benefit from rehabilitation efforts with a strong information component from those who are not (Study III). However, only the Monitoring concept appeared to be useful. There are several relevant methodological considerations here. Three scores can be derived from the MBSS. By summing up all monitoring items, patients can be divided in low vs. high Monitors. High and low Blunters are derived by summing all blunting items. Another possibility is to derive a sum score by subtracting the total blunting score from the total monitoring score, defining patients as Monitors or Blunters. Less than half of the patients
could be classified as high Monitors or high Blunters on the basis of the sum score (Study III). Other authors have also noted this difficulty (Johnson et al., 1996). There is no MBSS manual providing cut-off scores. The mean and median values were therefore used for dichotomising the patient groups into Monitors or Blunters. An empirically validated cut-off score may have yielded another grouping of patients, resulting in a more discriminative categorisation.

Another problem is that the MBSS questions are of a hypothetical nature. An interesting finding was that many patients who were retired, had difficulties imagining themselves in the work situation, which was no longer appropriate for them, but had no difficulties imagining the hostage situation. Other authors have pointed out the difficulty of imaging the hypothetical situations (Ross & Maguire, 1995). Another approach would be to use medical situations that are more similar to situations with which patients are familiar (van Zuuren et al., 1996). It should be noted that only marked items were summed. If a statement is not marked, it is unclear whether it is a missed item or whether it does not apply. Another problem is that of 14 items endorsed by <100 patients, 12 were Blunter items. Using the sum score method, very few blunting situations needed to be marked for a patient to be classified as a Blunter cf. (van Zuuren & Wolfs, 1991). Thus, the validity of this classification can be questioned. This may have contributed to the finding that the Blunting category was less useful in the present study.

Study IV was designed to explore quality of life aspects that could be used as indicators of rehabilitation needs one year later. In that study, only 22-24% of the total variance was explained. A number of methodological factors may have contributed to this. Uniformly high levels of PF, EF, and QoL is one explanation for the small portion of explained variance in the final regression models. These dependent variables were positively skewed, but attempts to deal with this by scale transformation did not normalise distributions. Insufficient
reliability of the scales used may be another explanation. Chronbach alpha for PF was 0.60 and 0.86 for EF. Thus, the EF scale had a high homogeneity, whereas the value for PF was lower. Dichotomisation reduced the variation in some variables (extensive treatment, advanced disease, HADS scores). An alternative would have been to dichotomise all variables and to perform a logistic regression analysis. However, since no convention exists for cut-off scores for the PF, EF, and QoL subscales, this alternative was discarded. Some potentially important variables were not included in the analyses, e.g. income status. Not all patients had completed that item, and including this had reduced the number of patients in the regression analyses.

An important question concerns the extent to which RF, EF and QoL can be considered relevant indicators of rehabilitation needs. They were chosen since a cancer disease and its treatment may affect physical, psychosocial and vocational components of individuals’ lives (Mellette, 1993). Also, the GR programme included components aiming at improving physical (physical training) and emotional function (CBT).

In Study IV, the entire sample of patients who had completed the relevant assessments was included. A potential threat to the internal validity of the Study IV findings is that 75 % had received or at least been offered interventions aimed at improving quality of life. In order to control for this, the variable Randomisation was added first to the analyses. In no point in these analyses did this variable display significant associations with either of the dependent variables.
CLINICAL IMPLICATIONS AND FUTURE RESEARCH

The results of Study I indicate that many cancer patients perceived benefits of participating in the GR programme and that most components of the programme were easy to understand. This suggests that the GR programme deals with issues important to patients that are difficult to cover in the ordinary, busy medical environment. Many patients come to the hospital only for medical treatment. The possibilities for encountering others in the same situation are limited. This is true also for getting extensive information about the disease and treatment, and their effects on everyday life without having the feeling of taking time from busy doctors and nurses. Also, in standard care, there are very few opportunities for cancer patients to participate in physical training, designed explicitly for them. It should be noted that the psychological component of the GR programme was rated as less beneficial than other components. Together with the results of Study II, the implication is that psychological interventions should be offered only to those in need, i.e. patients screened for psychosocial problems.

The GR programme reduced anxiety, depression, intrusion and avoidance among prostate cancer patients classified as Monitors on the basis of the MBSS (Study III). No effect, positive or negative, was found among the Blunters. This finding suggests that the GR programme may be well suited for periods of uncertainty, e.g. when prostate cancer patients have to decide on treatments. The present findings on this point need to be replicated before implementation in clinical practice is warranted.

In future research, other outcomes than those assessed in the present study would be preferable. As the level of quality of life was high, and levels of anxiety, depression, intrusion and avoidance were low, there was little room for improvement. It might be that other
measures, e.g. of well-being would have been relevant here. This is not unlikely, since well-being was shown to partly predict aspects of HRQOL one year after diagnosis. In the present study, well-being was assessed only at inclusion and was not monitored during the whole study period. Thus, no changes can be reported. Also, possible positive aspects of confronting a serious disease have not been assessed.

In general, it is important to carefully establish the “targets” of interventions that are to be evaluated in outcome studies. Thus, the outcome measures should be chosen according to some pre-existing notion about the processes or mechanisms by which the intervention is supposed to exert its effects. It is possible that the more or less routine inclusion of measures of anxiety, depression and quality of life in cancer rehabilitation studies should be questioned. Measures of hope, optimism and everyday moods may be of interest here.

Study IV illustrates that long-term HRQOL (PF, EF, global QoL) of cancer patients can be predicted, at least partly, by information available in conjunction with diagnosis. This information, also including the identification of psychological problems at diagnosis, and low self-rated well-being should be used when directing the limited recourses in health care to the groups with the greatest needs.

Several review articles have demonstrated positive outcomes of psychosocial interventions among cancer patients (Andersen, 1992; Bottomley, 1997b; Cwikel & Behar, 1999; Devine & Westlake, 1995; Fawzy et al., 1995; Krupnick et al., 1993; Meyer & Mark, 1995). Having many research-based interventions from which to draw upon is helpful for clinicians in their care of patients. However, usually they must answer the question: "Which of several interventions should I choose in view of the limited resources?" The Support-Care-
Rehabilitation-project has demonstrated that it was possible to implement several interventions for newly diagnosed patients with breast, GI or prostate cancer and that a large proportion of patients perceived benefits of the interventions. Based on the results from this and other theses from the project (Hellbom, 2001; Johansson, 2000; Persson, 2002), a possible model would be to facilitate a first contact between patients and their home care nurse (Johansson, 2000) and for patients who so wish, individual contacts with a psychologist (Hellbom, 2001) as early as possible after diagnosis. For patients with GI cancer, contact with a dietician (Persson, 2002) should also be offered. When treatment is ongoing or completed, approximately four months after diagnosis, a group educational programme, including information about cancer and treatment, and how this is likely to affect daily life, should be offered to all patients. The group programme should include physical exercise and relaxation techniques. The CBT component should be offered only to patients with demonstrated psychosocial needs.

It should be possible, in spite of limited resources, to implement psycho-educational rehabilitation groups at many hospitals. If a programme is established, a nurse should have the responsibility to inform the patients about this possibility. She should be the co-ordinator with whom patients should register for the groups. When enough patients (8-12) where gathered, the nurse should arrange the dates with the professionals involved (e.g. physician, dietician, physiotherapist) and invite patients. At most hospitals, this intervention should only take a few hours per professional and year. Maybe this would lead to more satisfied patients, taking a more active part in their treatment and care. It is important to continuously evaluate such programmes.
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REFERENCES


