Summary

Despite the life-threatening nature of the illness, many cancer patients seem to be able to cope well with the diagnosis and the treatment. However, cancer and its treatment often go hand in hand with physical, psychological and social problems. Fatigue is one of the most important complaints expressed by cancer patients. After treatment, around 30% of the patients experience so many problems in the field of quality of life that they require professional support to help them deal with these.

Oncological rehabilitation is one form of support. The number of cancer patients in the Netherlands requiring rehabilitation is expected to rise from 5000 in the year 2000 to 7000 in 2015. There is still much uncertainty concerning the effect of cancer rehabilitation on the quality of life. For example, it is unclear why some people benefit from cancer rehabilitation while others do not. This doctoral thesis is the first in the Netherlands to devote attention purely to oncological rehabilitation. The aims of this thesis are to examine the effect of cancer rehabilitation on the quality of life and on the degree of fatigue experienced by cancer patients, and to gain more insight into the factors that are related to the quality of life and the feeling of fatigue before and after cancer rehabilitation.

Chapter 1 describes the background to the study. A concise picture of cancer and cancer treatment is sketched, as well as the consequences of these for the quality of life of cancer patients. The chapter further discusses the concept of ‘quality of life’ and the need for professional support such as forms of psychosocial and physical intervention. The relevant literature indicates that such intervention has positive effects upon physical and psychosocial problems and consequently upon the quality of life of cancer patients. From this intervention, a transition is made to multidimensional oncological rehabilitation, based on the notion that the multidimensional problems of cancer patients may be effectively treated by means of a programme that consists of several components. The problems of the cancer patients are charted with the help of the International Classification of Functioning, Disability and Health (ICF) model. Subsequently, an overview is provided of the thesis, which is primarily oriented toward research of the effect of a multidimensional rehabilitation programme that was developed in 1999. The last chapter of the thesis devotes attention to the development of a physical training programme for cancer patients that was developed for a national follow-on study.

The multidimensional programme that was developed consists of physical training, sport and games, psycho-education, and information. The programme is implemented in a group setting, and is intended for adult cancer patients with various forms of cancer whose cancer-related treatment has been completed, who have a life expectancy of more than a year, and who have been referred for rehabilitation. This last element implies the presence of persistent physical or psychosocial complaints that have been determined by a doctor.

Chapter 2 examines the effect of the intensive part of the multidimensional rehabilitation programme (the first 6 weeks) on physiological functioning and the
quality of life. The study expected that the intensive part of the programme would have a positive effect on the quality of life and would also bring physiological improvements. Thirty-four patients participated in this study. Two thirds of those were women with breast cancer, the average age was 53 years. The results showed that the most common reasons for referral were a reduced exercise capacity and fatigue. The participants turned out to be perfectly capable of following the programme and the drop-out rate was low (8%). After 6 weeks, statistically significant improvements were found in measurements of physical capabilities such as oxygen pulse, oxygen uptake, muscle strength and muscle fatigue, but not in dyspnoea. After 6 weeks, significant improvement was also found in various physical and psychosocial domains of the quality of life. Moreover, patients reported significantly less fatigue in a number of domains. The hypothesis that the intensive part of the programme would result in physiological improvements was confirmed. The hypothesis that the intensive part of the programme would result improvements in quality of life was confirmed in a number of domains of both disease-specific and generic quality of life and degree of fatigue. On the basis of these results, the conclusion can be drawn that a 6-week intensive multidisciplinary rehabilitation programme is feasible and effective. Despite the fact that it was not possible to examine the effect of the separate components of the programme, the physiological improvements found do indicate that they can be attributed to physical training.

Chapter 3 researches the effect of the total multidimensional programme on the quality of life and on the exercise capacity. At the same time, the participants’ appreciation of the programme was also studied. Because patients are increasingly being regarded as experts in the field of their own health, the aim was also to obtain more insight into the preferences of patients for mono- or multi-dimensional rehabilitation. Accordingly, in the study, after group randomization, half of the groups were offered a multi-dimensional programme, while the other half could choose the programme components they wished to follow. Eighty-one patients participated in this study, the average age was fifty-two years, sixteen per cent of the participants were male, and two-thirds of the participants were women with breast cancer. The drop-out was twenty-two per cent and primarily related to a recurrence, and was not associated with age, gender, diagnosis, and time since treatment or diagnosis. The study population appeared to have significantly more problems in the field of quality of life than a matched reference group of cancer patients who had not been referred for rehabilitation, and more than the normal Dutch population. Ninety-seven per cent of the participants scored above the cut-off psychological distress score. Muscle-strength tests indicated that the strength of the lower extremities in particular had diminished. The results after the completion of the programme showed significant and clinically relevant improvements in all domains of quality of life, most of which also persisted into the follow-up measurement three months later. The maximum cycling ergometric tests and muscle-strength tests demonstrated significant improvement after the completion of the programme. No differences were found in the results between men and women, nor between the women who had breast cancer and people who had a different form of cancer. The patients were satisfied with the entire programme and also with the various components of the programme. An interesting finding was that most patients who had the opportunity to make a choice between the different components of the programme tended to choose the entire programme rather than only a part of it. At the completion of the programme, the majority of the participants would again choose the entire programme.
if they were asked, although the percentage of people who opted for a multidimensional programme after the completion of the programme was lower than it was before the start. On the basis of the results of the study, it can be concluded that the referred patients have a low quality of life and that the programme has a positive, significant and clinically relevant effect on the quality of life in terms of physical, psychological and social functioning. In addition, a multidimensional programme appears to be feasible for a broad group of patients. Finally, if patients are offered the choice, the majority will opt for multidimensional rehabilitation.

Chapter 4 attempts to acquire more insight into variables that are correlated to improvements in the quality of life. For this reason, both prior to and after the rehabilitation programme, the relationship between a number of sociodemographic data and personal resources such as social support (external resource) and self-efficacy (internal resource) on the one hand, and the quality of life, on the other, was studied. At the same time, investigation was performed into whether or not the programme had an effect on the personal resources. Prior to the study, it was expected that, besides the positive effect on the quality of life, the programme would also have a positive effect on the social support experienced and on self-efficacy. Due to the group-oriented approach, it was expected that the programme would have a positive effect on the social support experienced because contact with peers facilitates processes of social support and social comparison. It was expected that the physical training programme and the psycho-education would have a positive effect on self-efficacy because this form of control arises on the basis of success experiences in the performance of tasks, vicarious experiences, verbal persuasion, and physiological arousal. With regard to the relationship between the personal resources and the quality of life, it was expected that the personal resources would have a positive effect on the physical, psychological and social functioning of the participants. The results showed that the referred patients experienced more negative social support than a reference group of recently-diagnosed patients, and more than the normal population. The referred population also experienced more positive social support than the normal population but less than the reference group of newly-diagnosed patients. Further, at the conclusion of the programme, a statistically significant reduction in positive social support seemed to have occurred while no change in negative social support and self-efficacy was found.

People with more negative social support reported poorer social functioning prior to the programme and poorer physical, social and psychological functioning after completion of the programme. Negative support, as experienced prior to the programme, also had a negative effect on mental functioning after the programme. People with a high degree of self-efficacy reported better mental functioning prior to the programme and better physical and mental functioning after the programme. Furthermore, the quality of life prior to the rehabilitation programme turned out to be the best predictor for the quality of life after the programme. Finally, reduction in negative social support and improvement in self-efficacy seemed to be related to improvement in the quality of life. On the basis of the results, it can be concluded that the rehabilitation programme has little effect on the personal resources of the participants, although a question mark may be inserted against the sensitivity of the questionnaire for measuring this self-efficacy. Further, negative social support and self-efficacy turned out to be more consistent predictors of the quality of life than positive social support. Finally, the conclusion can be drawn that although the programme does not lead to improvement in self-efficacy and to a reduction of negative social support at group.
level, improvement in the quality of life at individual level is associated with increased self-efficacy and diminished negative social support. Accordingly, the recommendation is made that future programmes ought to be structured with the aim of improving self-efficacy and reducing negative social support. A practical implication of the study is also that cancer patients who experience much negative social support form a high-risk group in terms of poorer functioning and therefore ought to be given more attention.

In view of the fact that fatigue is one of the most commonly reported complaints after cancer has been diagnosed, Chapter 5 presents a study on the fatigue of patients who have been referred for rehabilitation. Fatigue is regarded as a multidimensional construct and the primary aim of the study is to research the effect of diverse variables on fatigue prior to rehabilitation. A second aim is to study the effect of the multidisciplinary rehabilitation programme on fatigue, and to investigate if, and to what extent, any change in fatigue after an intervention is related to changes in predictors that have been identified prior to rehabilitation. Within 72 patients, the relation between the different variables and the five different dimensions of fatigue was examined prior to the intervention. The effect upon fatigue of demographic variables, disease and treatment-related variables, anthropometric data, physiological variables, physical and psychological distress symptoms, and experienced functioning was investigated. Analyses indicated that various dimensions of fatigue were related to various physical and psychosocial parameters, which underlines the multidimensional nature of fatigue. Further analyses showed that the maximum workload, physical symptoms, the experienced physical functioning, mental functioning, role limitation on the basis of physical functioning, and self-efficacy were the most important predictors of fatigue at the baseline. The results of the 56 participants who had completed the programme further indicated that the rehabilitation programme had positive and, more importantly, clinically relevant effects upon all dimensions of fatigue. The largest reduction in fatigue was found in the physical dimension. Furthermore, it turned out that fatigue prior to the rehabilitation programme was the most important predictor of fatigue after the intervention. Finally, it was found that fatigue prior to the rehabilitation programme was the most important predictor of fatigue after the intervention. Despite the fact that it was not possible to investigate the effect of the various programme components, the findings seem to support the recommendation that future interventions ought to include a physical training component.

Chapter 6 describes the development of a physical self-management programme. This programme was developed for a national randomized controlled trial (RCT, the Onco-Rev study) which investigates, between 2003 and 2007, the effects of a multidisciplinary rehabilitation programme on the quality of life and compared it to physical training and to a (waiting list) control group. The aim of the study outlined in this thesis is to develop a physical training programme whose content and delivery are based upon the best available evidence. For the content of the programme, four frequently-occurring, related, but conceptually and empirically different physical problems of cancer patients were distinguished, namely, a reduced aerobic capacity, diminished muscle strength, fatigue, and role limitation due to physical problems. A study of the relevant literature was performed to find evidence of the effect of exercise programmes on aerobic capacity, muscle strength, fatigue and limited physical (role) functioning. With regard to the delivery, investigation was carried out into differences in evidence with regard to individual
versus group-oriented programmes, local fitness exercises versus sport programmes, and self-management or self-efficacy-enhancing programmes versus traditional interventions. With regard to the effect of exercise, the study produced findings that varied from evidence at RCT level for muscle strength to evidence at meta-analysis level for fatigue, physical (role) functioning, and aerobic capacity. With regard to the delivery, no evidence was found for differences in the effect between individual and group programmes, or between local exercise and sport. There was evidence at meta-analysis level that self-management programmes and programmes with self-efficacy-enhancing techniques have positive effects on health-related outcomes with various chronic illnesses, on the quality of life among cancer patients, and on exercise therapy adherence and the adoption of physically active behaviour. The rehabilitation programme was developed on the basis of the best available evidence with regard to the content and the delivery. The possible advantages of the programme are (a) tailor-made physical training oriented to the established problems of the patient, (b) the delivery of the training as a self-management programme that can have positive effects on health-related outcomes, the quality of life, exercise adherence, and a physically active lifestyle in the long run.

In Chapter 7, the results of the study are placed in a broader context. Attention is devoted to the most important findings, methodological considerations, clinical implications, and future research.