Summary
Men who are diagnosed with testicular cancer are generally young. As a consequence of the treatment they receive nowadays, they are likely to cure from the disease, even when they have metastases. This means that they have to live with possible short- and long-term sequel of diagnosis and treatment for many years. Survivors who do not have the resources necessary to cope with such physical and psychosocial sequel, may find it more difficult to adjust to their altered life situation and experience an impaired quality of life. These men might need professional assistance to enhance their skills to competently manage their lives as a cancer survivor. Yet, how do health care providers know which testicular cancer survivor is at risk for distress and might benefit from an intervention? Therefore, it is needed to investigate factors predictive of quality of life, in order to detect and refer at risk individuals to an appropriate intervention. The aim of this thesis was to examine the quality of life of testicular cancer survivors and to identify risk factors for an impaired quality of life.

The introductory chapter (chapter 1) elaborates on the concept of quality of life and the possible effects of cancer on the quality of life of patients and survivors. After that, the working model that was used as a framework for the study is introduced, and an overview of the chapters is presented.

The second chapter of the thesis describes a critical review of the current state of knowledge on the physical, psychological and social well-being of testicular cancer survivors. A literature search identified 23 studies that met the inclusion criteria. These studies were published between 1980 and 2003 and most of the studies suffered from methodological shortcomings (e.g., small sample sizes, non-validated questionnaires). Therefore, a quality assessment, using methodological and disease- and treatment-related criteria, was performed to distinguish stronger- from poorer-quality studies. Seven studies appeared qualitatively stronger. Results showed that the majority of the survivors in both stronger- and poorer-quality studies reported a good quality of life. Prospective and retrospective studies showed that quality of life increased after completion of treatment and that negative consequences (e.g., fatigue, distress, fear of tumor recurrence) on life decreased as compared to the situation directly after diagnosis. The stronger-quality studies paid little attention to the social dimension of quality of life (marital functioning, social support, and functional life) and to positive effects of the experience with testicular cancer. Poorer-quality studies reported that, besides a decrease in negative consequences of testicular cancer on the patients’ life, the experience of testicular cancer had positive effects also (e.g., emotional growth, stronger relationships with family and friends).

Based on this review, one could assume that testicular cancer survivors generally experience a good quality of life. However, it seemed not justified to draw such a conclusion, because of the methodological shortcomings of most studies and because the stronger-quality studies did not investigate all dimensions of quality of life with the same extensiveness. Therefore, it was suggested that future research should include large groups of both short- and long-term survivors, sociodemographically matched comparison groups, and validated questionnaires. These methodologically stronger studies should focus on
the identification of risk profiles, to detect distressed individuals possibly in need of professional psychosocial care.

The study described in chapter 3 aimed to assess the quality of life of testicular cancer survivors and attempted to overcome some of the methodological shortcomings identified in the review. The first goal was to compare the quality of life of testicular cancer survivors (n = 354; range in time since completion of treatment = 3 months to 25 years) to that of a reference group of Dutch men. Secondly, it aimed to identify survivors with an impaired quality of life, based on sociodemographic variables, disease- and treatment-related variables, and recently experienced life events. Results showed that, on the whole, testicular cancer survivors experienced a quality of life similar to that of the reference group of Dutch men. Furthermore, quality of life was comparable among the short-, median-, and long-term survivors, those treated with surgery alone and those treated with more extensive treatment, and those who had experienced a second cancer event and those who had not. Survivors at somewhat higher risk for an impaired quality of life were older and had experienced more negative life events. Yet, the combination of unemployment and presence of a chronic disease appeared to be the strongest predictor for an impaired quality of life. Responses to an open question indicated that the unemployed survivors with a chronic disease significantly more often experienced a negative impact of testicular cancer on their current quality of life than their counterparts.

In conclusion, it appears that testicular cancer survivors generally experience a good quality of life. The lack of effect of objective disease- and treatment-related variables suggests that survivors quickly adapt to the circumstances created by the experience of cancer and its treatment, even after extensive treatment or a second cancer event. The joint burden of unemployment and chronic disease on testicular cancer survivors’ quality of life has also been found in the general population. This finding makes sense when it is considered that chronic diseases can cause impairments in social activities and work, which may lead to lower levels of quality of life. Nevertheless, the variance explained by the studied variables was low, indicating that more important predictors remain to be identified.

Having a sense of meaning has been identified as an important contributor to a person’s psychosocial well-being. People with a strong sense of meaning view their life from a meaningful perspective, which forms a guide from which goals are directed. People try to fulfill these life goals. Testicular cancer survivors may find it difficult to attain meaning to their cancer experience and, because of the short- and long-term after effects of the diagnosis and treatment, some goals may become unattainable. This may have a negative impact on their quality of life and cause distress. The first aim of the study described in chapter 4 was to assess the sense of meaning of testicular cancer survivors. The second aim was to investigate if the cancer experience had changed the survivors’ outlook on life. The third aim was to assess the relative contribution of meaning in the prediction of psychosocial well-being and cancer-related distress, in addition to sociodemographics, disease- and treatment-related variables, concurrent chronic disease, and recently experienced life events. Results showed that testicular cancer survivors experience life as meaningful. In line with the literature, it was found that single survivors, as well as childless survivors, those without employment, those with a chronic disease and those who had experienced
more negative life events experienced somewhat less meaning than their counterparts. Disease- and treatment-related characteristics were not related to meaning. Approximately two-third of the survivors experienced a change in outlook on life; a majority (60%) reported a more positive outlook on life since the disease. Meaning was the most important predictor for psychosocial well-being, but it appeared to have only a weak effect on cancer-related distress.

In sum, testicular cancer survivors appear to have a strong sense of meaning, and this sense of meaning is more important for their psychosocial well-being than sociodemographics, disease- and treatment-related variables, concurrent chronic disease and recently experienced life events. The effect of meaning on cancer-related distress was less strong, suggesting that it might be more important to the experience of a positive quality of life than to coping with cancer-related distress. Yet, prior research has suggested that meaning may serve as a protective factor against cancer-related distress. Therefore, further research might focus on the underlying mechanisms through which meaning and cancer-related distress relate.

A cancer experience can be so distressing that it produces specific cancer-related psychological symptoms, such as intrusive and emotionally upsetting thoughts and memories of the disease period and the avoidance of unpleasant feelings and recollections. These cancer-related stress symptoms can persist months or even years after completion of treatment and they may have a negative impact on the daily life of the survivors. Cancer-related stress symptoms have never been studied among testicular cancer survivors. Therefore, the primary goal of the study described in chapter 5 was to investigate the prevalence of cancer-related stress symptoms among testicular cancer survivors. The secondary goal was (a) to gain quantitative insight into the extent to which sociodemographics, disease- and treatment-related variables and concurrent chronic disease are associated with levels of cancer-related stress symptoms and (b) to assess qualitatively whether concrete events and subjective perceptions relate to the experience of cancer-related stress symptoms. Responses to the questionnaire showed that 13% of the 354 testicular cancer survivors experienced cancer-related stress symptoms to such an extent that psychosocial care is recommended. Single testicular cancer survivors, those with less education, and those who were not employed for wages reported somewhat higher levels of cancer-related stress symptoms. Time since treatment, type of treatment, the experience of a second cancer event and concurrent chronic disease appeared to play almost no role. Based on the answer patterns to the questionnaire, two groups were selected for an interview: 15 survivors with clinically elevated levels of cancer-related stress symptoms and 15 without these symptoms. The interview focused on the relationships between concrete events (e.g., undergoing an ultrasound) and subjective perceptions (e.g., anxiety about future medical problems) and cancer-related stress symptoms. Results showed that the number of cancer-related events recalled by survivors with clinically elevated levels of cancer-related stress symptoms differed little from those without these symptoms. However, those with clinically elevated levels of distress did report being more upset by the recollection of such events. Also, they reported that they were more upset by the effects of their illness, in the sense that it had caused more changes in their daily life and that they were anxious about the possibility of additional medical problems in the future. The testicular cancer
survivors with clinically elevated levels of cancer-related stress symptoms indicated that their life was still threatened by the cancer experience.

In sum, the data indicate that an important subset of testicular cancer survivors experiences cancer-related stress symptoms. Sociodemographics and disease- and treatment-related variables appear not to be strong indicators of cancer-related stress, whereas the impact survivors feel on their current life and anxiety about the future does seem to give an indication of the presence of stress symptoms. These findings may offer new directions for communication between health care providers and survivors. Assessment of thoughts concerning threats of cancer and perceived effects on their current and future life may give better insight into distress testicular cancer survivors experience than the actual medical history. Testicular cancer survivors who indicate that they perceive that their life is still threatened might benefit from a psychosocial intervention that focuses on replacing unrealistic beliefs with realistic beliefs.

Fatigue is one of the most prevalent sequel of cancer and its treatment and it is known for its potential negative effects on the well-being of patients and survivors. The study described in chapter 6 is the first to examine the prevalence of and changes in different domains of fatigue among testicular cancer patients during the first year after orchidectomy. Furthermore, relationships between fatigue on the one hand and sociodemographics, hemoglobin- and testosterone levels, and trait anxiety on the other hand were studied. Fifteen patients treated with orchidectomy and 37 treated with orchidectomy plus chemotherapy were assessed within one month after orchidectomy, 3 months later (which was immediately after chemotherapy for the chemotherapy group), and 12 months after orchidectomy. Results showed that testicular patients did experience more fatigue immediately after orchidectomy and, for those who received chemotherapy, following completion of chemotherapy. One year after orchidectomy, patients treated with orchidectomy alone as well as those treated with orchidectomy and chemotherapy reported levels of fatigue comparable to those of individuals without a history of cancer. Older age related (moderately) strong to increased fatigue. Earlier levels of fatigue were predictive of later levels of fatigue. Furthermore, concurrent and prospective effects were found of trait anxiety on fatigue. The numbers of patients suffering from anemia or low testosterone levels appeared small. Therefore, we could not examine the impact of these variables on fatigue levels.

In conclusion, testicular cancer survivors seem to experience the highest levels of fatigue shortly after orchidectomy and chemotherapy. Fatigue does not seem to be an enduring problem for the majority of the patients, irrespective of treatment received. Older patients, those who already reported being fatigued shortly after orchidectomy, and those with a more anxious disposition are at risk for cancer-related fatigue. These patients might benefit from a multidisciplinary intervention that focuses on physical exercise training and the strengthening of coping strategies to effectively reduce fatigue.

In chapter 7 a methodological issue is addressed. In quality of life studies, several methods are used to recruit patients. Many studies recruit patients through hospital databases, but there are also studies that approach support groups, use the internet or an advertisement in papers or magazines as a recruitment source. Recruitment through different sources
may identify populations with different characteristics and this may bias the outcomes. Until now, little empirical attention has been paid to the impact of recruitment source on quality of life. Therefore, this study aimed to gain insight into (1) individuals that different recruitment sources identify and (2) the effect of recruitment source on quality of life. To do so, we compared testicular cancer survivors recruited through a patient association (n = 85) with those recruited through the UMCG database (n = 354) on sociodemographics, disease- and treatment-related characteristics and quality of life. Results showed that members from the patient association were significantly younger, more recently treated, higher educated, more often treated with extensive treatment, had more often experienced a second cancer event, and reported a worse functioning on most of the quality of life domains than those recruited through the hospital group. Even after controlling for sociodemographic- and cancer-related variables, a worse functioning on most of the quality of life domains was found in members from the patient association as compared to those from the UMCG database.

In conclusion, the results of this study support the notion that different recruitment methods identify individuals with different sociodemographic and disease- and treatment-related characteristics and different quality of life scores. However, differences in sociodemographic and disease- and treatment-related characteristics do not seem to determine these quality of life differences. This indicates that there must be other factors that cause the differences in quality of life between groups. These results may warn researchers to be careful with recruitment, because it may lead to selection bias that has consequences for the generalizability of the results. If results cannot be generalized, it is not possible for the clinician to give solid advice to patients on relevant issues.

Finally, in chapter 8 the main findings of the studies described in this thesis are discussed and placed within a broader context. This chapter also reflects on methodological issues. Furthermore, the usefulness of the model that was used as a framework in this thesis is discussed and suggestions are made about directions for future research. The chapter ends with a discussion on the implications of the findings for clinical practice.