chapter 9 **summary**

Testicular cancer, the most common malignancy in young men, is a highly curable disease: almost 90% of patients is cured, even when the cancer is disseminated. As a result, the group of testicular cancer survivors is growing. These survivors have to face possible sequel of disease and treatment for the rest of their lives. However, they are not alone in this experience. A cancer diagnosis has an impact on the spouse and other family members as well. Quality of life is a multi-dimensional concept that reflects an individual's perception of his physical, social and psychological well-being. A number of studies on testicular cancer patients have also included spouses and paid attention to their quality of life and psychosocial functioning. Unfortunately, these studies included small numbers of spouses and examined adaptation on group level, which does not provide insight into functioning in pairs. Little attention has been paid to single testicular cancer survivors and no attention to survivors who develop a relationship after treatment is completed. This thesis addressed the psychosocial functioning of spouses of testicular cancer survivors (and that of themselves) and correspondence within couples (Chapters 2, 3, 4 and 5) as well as possible differences in functioning of survivors according to relationship status (Chapters 6 and 7). Men treated over a period of 25 years and their spouses were included, as well as a group of patients and spouses who were followed during their first year after diagnosis.

A cancer diagnosis is often so distressing that it can result in stress response symptoms. These symptoms comprise of intrusive and emotionally upsetting thoughts and memories of the disease period and the attempt to avoid those recollections, even years after treatment has ended. The aim of the study described in *Chapter 2* was to investigate the stress response symptoms and quality of life of spouses of testicular cancer survivors and the correspondence within couples.

Two hundred and fifty nine couples of testicular cancer survivors who were treated between 0,5 and 25 years before start of study, and their female spouses participated. A group of spouses was included that had not been the focus of study before: spouses who developed a relationship with the survivor after his treatment was completed (n=40). The range of time since completion of treatment in this study was very large, but it appeared unrelated to quality of life or stress response symptoms of spouses.

Spouses experienced better physical functioning than the average Dutch woman, maybe as a result of a different frame of reference: a husband who won his fight against cancer. Differences were found between spouses who were present during the period of diagnosis and treatment (long-term spouses) and spouses who had started a relationship with the survivor after completion of treatment (new spouses). New spouses reported more problems with psychological quality of life domains than long-term spouses and the average Dutch woman. Additionally, they reported low levels of intrusions related to their husband's cancer even though they were not present at time of diagnosis and during treatment. Long-term spouses reported moderate levels of stress response symptoms, and 14% reported clinically ele-

vated levels for which an intervention might be helpful. Spouses of men who received combined treatment experienced more stress response symptoms than spouses of men who only had surgery. Level of stress response symptoms was related within couples, but spouses reported more stress response symptoms than the testicular cancer survivors themselves. This study showed that spouses who were present at time of diagnosis and treatment reported having a good quality of life and moderate stress response symptoms. However, functioning of new spouses is poorer than that of long-term spouses and the average Dutch woman on various quality of life domains, particularly the psychological. Research into the processes of building up a relationship after surviving cancer might provide more insight into these results.

Chapter 3 deals with the marital and sexual satisfaction of testicular cancer survivors and their spouses. Until now, studies on sexual satisfaction after testicular cancer mainly focussed on the survivors themselves. No attention was given to possible consequences for spouses and correspondence within couples. This study focussed on possible differences in marital and sexual satisfaction between couples who were married or cohabiting before the diagnosis (long-term couples) and couples who developed a relationship after his treatment was completed (new couples), between couples and reference groups, and between survivors and spouses. We also examined associations between treatment-related factors and marital and sexual satisfaction. Lastly, couples indicated whether they experienced any changes in their relationship due to their experience with testicular cancer. Two hundred and nineteen long-term couples and 40 new couples were included.
Survivors in a new relationship reported less sexual satisfaction compared to the survivors who had a long-term spouse. For spouses no differences in satisfaction were found according to onset of the relationship. Survivors and spouses experienced similar marital satisfaction as reference groups of men and women. However, all survivors and the long-term spouses reported less sexual satisfaction than these reference groups. Clinical relevance of the differences in sexual satisfaction found appeared to be small, indicating that an intervention is not necessary for all couples. Only one risk factor for decreased sexual functioning was found. In long-term couples, both survivors and spouses experienced less sexual satisfaction when the survivors experienced a second cancer event (either a second diagnosis of testicular cancer or another cancer diagnosis). With respect to correspondence within couples, differences were found between long-term and new couples. In long-term couples, marital satisfaction was moderately related, and sexual satisfaction was highly related. Twelve percent of survivors experienced such low marital satisfaction that counselling is recommended, in contrast to 22% of the spouses. Marital satisfaction of spouses was less than that of survivors. In new couples, marital satisfaction was weakly related, and sexual satisfaction was strongly related. Survivors and spouses experienced similar marital and sexual satisfaction. Nevertheless, in this group, more survivors (25%) than spouses (18%) reported such low marital satisfaction that counselling is recommended. Almost half of the long-term couples reported no change

in their relationship following the cancer experience, and more than 40% reported that it had improved. Only a small percentage of survivors and spouses felt that their marriage had deteriorated. In new couples, the majority of survivors (57%) and spouses (54%) reported that the husband's experience with cancer had a small or no influence on their relationship. Couples facing testicular cancer may benefit from information on possible sexual consequences. Especially survivors who developed a relationship after completion of treatment seemed to form a vulnerable group. More research is needed to explore mechanisms underlying this vulnerability.

Chapter 4 deals with the expression of negative emotions such as anxiety, anger and depression. Previous studies reported that emotional expression was linked to several mental and somatic health benefits after cancer. This study focussed on expression of negative emotions in testicular cancer survivors and their spouses and its relationship with the functioning of survivors and their partners. Firstly, we examined differences in expression between survivors, spouses, and men not confronted with a cancer experience (controls). Secondly, we investigated the link between emotional expression and objective treatment related variables and thirdly the link between emotional expression of survivors and spouses and their own and the partner's functioning. We included three aspects of functioning: stress response symptoms, marital satisfaction and mental health. 219 long-term couples of testicular cancer survivors and their spouses, and 241 male controls participated in this study.

It appeared that male survivors expressed anxiety, anger and depression less often than men who did not experience cancer. This difference was highly clinically relevant, and suggests that the experience with cancer seems to be associated with a decrease in the expression of negative emotions. Spouses expressed negative emotions more often than testicular cancer survivors, but less than male controls. This finding might indicate that spouses too have been affected by the cancer experience and as a result express such emotions less.

What was striking in light of these findings, was the overall judgement of half of the survivors that they expressed emotions more often since the diagnosis. It may be that survivors express positive emotions like happiness, love and joy more often, but have changed the frequency of expressing negative emotions. A third of the spouses indicated that they express emotions a little or a lot more often since their husbands' illness, while half of the spouses reported no change in expression of emotions. Emotional expression of testicular cancer survivors appeared to be unrelated to several treatment aspects (time since completion of treatment, type of treatment received and the experience of a second cancer), indicating that the cancer experience in itself is more important in explaining differences in emotional expression.

With respect to correspondence within couples, it was found that emotional expression of survivors or that of spouses was unrelated to their own or to the other's stress response symptoms, marital satisfaction or mental health. It seems that after the experience with tes-

ticular cancer, survivors and their spouses express negative emotions less often. Emotional expression was unrelated to psychological functioning or satisfaction with the relationship, suggesting there is no need for interventions to facilitate expression.

The study described in *Chapter 5* was designed to longitudinally examine stress response symptoms and quality of life in couples confronted with disseminated testicular cancer. We studied adjustment in the first year following orchiectomy. Nineteen couples provided information on their functioning prior to start of chemotherapy (T1), after completion of chemotherapy (at three months, T2), and one year later (T3). Goals were to examine change over time in patients' and spouses' stress response symptoms and quality of life, to explore correspondence within couples, to examine possible predictive power of baseline levels of stress response symptoms and quality of life on later levels, and to examine differences in quality of life with reference groups.

Prior to chemotherapy, 26% of patients and 50% of spouses reported clinically elevated levels of stress response symptoms. Stress response symptoms in couples had decreased after completion of chemotherapy. At one year after diagnosis, stress response levels in patients were slightly higher again (16% reported clinically elevated levels), but in spouses they appeared to be lower than at three months (10% reported clinically elevated levels). With respect to quality of life, patients reported lowest physical and social functioning shortly following chemotherapy as compared to before chemotherapy and one year later. Mental health of patients was worst shortly before chemotherapy but improved over the year. Surprisingly, physical functioning of patients was better than that of the reference group before start of chemotherapy as well as one year later. Spouses' social functioning improved over the year and their physical functioning and mental health did not change significantly throughout the year. Spouses also experienced better physical functioning than the reference group before and after chemotherapy. Before start of chemotherapy, both patients and spouses reported worse social functioning as compared to the reference groups. Couples had comparable social functioning to that of the reference groups one year after diagnosis; they seem to have returned to their usual social activities. With respect to correspondence within couples, it appeared that the trajectory of functioning differed and that correlations between the functioning of patients and partners were moderate to very low. Stress response symptoms of patients and spouses were negatively related at baseline. When one partner was reporting more stress response symptoms, the other partner reported less. This might be a psychological mechanism through which spouses want to protect one another from their own distress. For quality of life only one relationship was found: social functioning in patients and partners was positively related after completion of chemotherapy, meaning that when one partner experienced better social functioning the other did also. For patients, earlier levels of stress response symptoms were strongly predictive of later levels while less individual stability was found in quality of life. For spouses earlier levels of stress response symptoms

were not predictive of later levels. Spouses were individually highly consistent in their reports of physical functioning and somewhat less consistent in mental health and social functioning. The effect of disseminated testicular cancer on the quality of life of patients and their spouses seems to be temporary. After one year, a minority may need clinical attention for stress response symptoms.

Being single appears to be a risk factor for psychological distress, and reduced self-esteem or body image problems after cancer. Being single might also result in the receipt of less social support, which can possibly affect mental health in a negative way. However, almost no research has been performed on differences in adjustment after cancer according to relationship status. The aim of the study described in *Chapter 6* was to examine possible differences in functioning between single survivors of testicular cancer, those with a continuing relationship from time of diagnosis (long-term relationship) and those with a spouse they met after completion of treatment (new relationship). Differences between these three groups were studied with respect to the amount of support received, satisfaction with support, self-esteem and mental health. We also studied whether social support and self-esteem are predictors of mental health in these three groups. A total of 129 survivors (fourty singles, fourty with a new relationship and fourty-nine with a long-term relationship) were included. All three groups indicated receiving a similar quantity of social support. However, satisfaction with support received was experienced differently. Survivors with a long-term relationship were most satisfied with support and singles least. Thus, although singles experienced the same quantity of support, they were less satisfied. This finding would suggest that their need for support was not fulfilled. Support from a spouse is probably more in line with the needs of testicular cancer survivors than support from others. Self-esteem and mental health also differed between the three groups. Survivors with the spouse they had at diagnosis reported the highest self-esteem and the best mental health. Survivors of testicular cancer who developed a relationship after completion of treatment did have higher self-esteem than singles, but comparable mental health. Survivors with a new spouse and singles had worse mental health than a reference group of men. The difference in self-esteem between singles and survivors of testicular cancer with the same spouse was the biggest and was clinically relevant. This result suggests that both singles and survivors with a new spouse have issues that negatively impact their psychological well-being. Underlying mechanisms for mental health should be explored further since mental health was predicted by different factors in the three survivor groups. Health care workers should be aware of the more vulnerable position that single patients with testicular cancer are in because they are at risk for a lowered mental health and self-esteem. In particular, leave room and opportunity to discuss concerns they have regarding their future.

Chapter 7 describes a study aimed to prospectively and longitudinally investigate sexual functioning during the first year following surgery. Again, the focus lies on possible differences in sexual functioning between single testicular cancer survivors (39% of sample) and those with a partner, but also on the relationship between sexual functioning and type of treatment and depressive symptoms. Patients from two large referral centres were asked to participate (the UMCG in the Netherlands and the MD Anderson Cancer Centre in Houston, USA). In total, 93 testicular cancer patients filled in the International Index of Erectile Function (IIEF) and CES-D after orchiectomy (T1) and 3 (T2) and 12 (T3) months later. It appeared that testicular cancer patients experienced changes in most aspects of sexual functioning over the year, except in desire. Orgasmic functioning, overall satisfaction and total sexual functioning changed according to a u-shaped pattern. Patients reported decreased functioning 3 months after removal of the affected testicle, followed by an increase in sexual functioning to above baseline level one year after diagnosis. Erectile functioning and intercourse satisfaction were comparable directly following orchiectomy and 3 months later, and improved to above baseline level after one year. Type of treatment received (75% of patients received chemotherapy in addition to orchiectomy) was unrelated to the different aspects of sexual functioning. Depression was most prevalent directly following orchiectomy, with 26% of patients suffering from clinically elevated levels indicating that they probably need professional care. After a year this percentage had dropped to 16. Depressive symptoms were weakly to moderately related to several aspects of sexual functioning shortly after surgery, but three and twelve months later only to overall sexual functioning. It also appeared that early depressive symptoms had no predictive power on later sexual functioning. Relationship status seemed to play a role in sexual functioning. Single testicular cancer patients reported worse sexual functioning at all measurement times as compared to patients having a partner in all but one aspect, namely desire. While the desire to be sexually active was the same in both groups, singles evaluated their actual functioning as worse. One year after surgery, singles also reported worse sexual functioning in 3 domains than norms, while patients in a committed relationship reported more intercourse satisfaction than norms. Even though differences between single patients and those in a relationship were statistically highly significant, effect sizes indicated that the differences were not clinically relevant. On the other hand, the worse functioning of singles as compared to norms was on the verge of being clinically significant. This suggests that functioning is problematic for single testicular cancer patients and that an intervention could be beneficial. Singles may encounter more insecurities regarding their sexuality and therefore may need more information and guidance.

Finally, in *Chapter 8* the main findings of the thesis are discussed, as well as methodological considerations, suggestions for future research and clinical implications.