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Surviving testicular cancer

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Document Version

Publisher's PDF, also known as Version of record

Publication date:

2008

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Tuinman, M. A. (2008). *Surviving testicular cancer: relationship aspects*. s.n.

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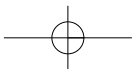
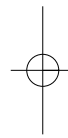
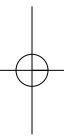
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surviving testicular cancer relationship aspects



RIJKSUNIVERSITEIT GRONINGEN

surviving testicular cancer: relationship aspects

Proefschrift

ter verkrijging van het doctoraat in de
Medische Wetenschappen
aan de Rijksuniversiteit Groningen
op gezag van de
Rector Magnificus, dr. F. Zwarts,
in het openbaar te verdedigen op
woensdag 3 september 2008
om 14:45 uur

door

Marrit Annika Tuinman

geboren op 9 juli 1975
te Groningen

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Marrit Tuinman
Surviving testicular cancer: relationship aspects
Thesis University of Groningen

Cover design Studio Frank en Lisa (www.studiofrank-lisa.nl)

Lay out Gery Hoekstra, IKNO, Groningen

Printed by Krips bv, Meppel

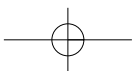
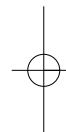
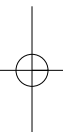
This research was supported by a grant from the Dutch Cancer Society (KWF Kankerbestrijding), no. RUG 99 2130

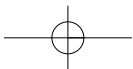
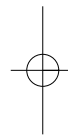
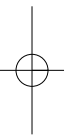
Financial support for this thesis was kindly given by
Stichting Werkgroep Interne Oncologie Groningen,
Integraal Kankercentrum Noord Oost, Groningen/Enschede and
the Dutch Cancer Society (KWF Kankerbestrijding)

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chapter 1 **introduction**





Testicular cancer

Testicular cancer is the most common malignancy in men aged 20 to 35 years (1). Around 25 years ago testicular cancer evolved from being the leading cause of cancer death in young men, into a highly curable disease. The enormous improvement in treatment results of testicular cancer can be mainly attributed to the introduction of cisplatin based chemotherapy in the late 1970s (2;3). Nowadays, almost 90% of testicular cancer patients is cured, even when the cancer is disseminated (4;5). Although testicular cancer is a rare disease (almost 1% of all new cancer diagnoses in men), the incidence is rising (6). Around 500 men are diagnosed with testicular cancer in the Netherlands each year (7). The University Medical Centre Groningen (UMCG) in the Netherlands is a tertiary referral centre for patients with testicular cancer. Considerable institutional research has been performed at the UMCG over the past 30 years with respect to epidemiology, genetic susceptibility, physical long-term toxicity such as cardiovascular diseases, sexual functioning and general quality of life issues (8-13). This thesis addresses the functioning of testicular cancer survivors treated at the UMCG between 1977 and 2003 and that of their partners. Particular focus will be on relationship aspects: the impact of the disease on the spouse, correspondence in functioning between partners and the difference in functioning between single survivors, those in a committed relationship, and those with a new partner.

Psycho-Oncology

Also around 25 years ago, a field of research emerged addressing the psychosocial aspects of cancer and its treatment: psycho-oncology (14-16). At first the psychological reactions of patients were studied, later attention shifted to partners followed by interest into the consequences for other family members and caregivers. After studying the functioning of people confronted with cancer, the field focussed on possible risk and resilience factors for physical, psychological, social and behavioural functioning and survival as well. With increasing survival results, through proper early detection or improved treatment, half of all cancer patients today have a 5 year survival (7). As a result of better survival, an increasing number of cancer survivors have to face possible sequel for the rest of their lives. Since the year 2000, psycho-oncological research also focuses on the quality of life of survivors and other survivorship issues (17). Currently, quality of life (QOL) is considered the second most important outcome in oncology research, after survival (18). It has recently been stated that randomized controlled trials in oncology should include validated measures of quality of life (19). Quality of life is a multi-dimensional concept that reflects an individual's perception of his physical, social and psychological well-being.

Cancer and social relationships, especially with the spouse

Research findings have shown the advantages of social support in dealing with stressful events: people with a partner, family members and friends who provide support have a better

quality of life than those who have fewer resources (20). Family members, and in particular the spouse, are the main source of support for cancer patients (21;22). However, family members of cancer patients have been found to be substantially distressed, not only because they have to cope with their own fears and insecurities regarding the disease, but also because of their supporting role (23;24). Attention therefore focussed on the impact of cancer on caregivers of cancer patients (very often the partner) (25), parents of children with cancer (26), children of a parent with cancer (27), and siblings of cancer patients (28). All these studies emphasize the major impact that a cancer diagnosis has on all family members, especially the spouse (29).

The impact of cancer on spouses of cancer patients has been studied fairly extensively, with varying findings. Spouses have been found to experience less distress, equal distress, and even more distress than patients themselves (24;30-34). Earlier studies on distress after cancer in patients and spouses studied reactions on a group level, which makes insight in correspondence impossible (32). Results from studies on adjustment on pair-level showed that distress within couples is not always related, it is possible that one partner's functioning improves over time, while that of the other remains the same (35-39). Besides gaining insight into correspondence, it is relevant to take gender of the spouse into account when studying distress after cancer. A difference has been reported in the functioning of male and female spouses (30). Female spouses specifically seem to be at risk for high levels of distress and adjustment problems, even more than patients themselves (34;40). This might be the result of the fact that caregiving and providing emotional support are more relevant for women's identity. Women more often feel that it is their task to provide support and as a result are more distressed when they feel they are not responding like they should (40). To date, the majority of psycho-oncologic studies on adjustment after cancer has been performed on breast cancer patients and their male spouses (41), and prostate cancer patients and their female spouses (42;43). Besides, many studies included small sample sizes (32;41), and focussed on short-term and not on long-term cancer survivors (44).

Relationship status and functioning of cancer patients

Being married is consistently related to better health and a reduction in the negative emotional effects of all types of life strain. The benefits are almost always greater for men than for women (45). It has been suggested that being married is related to lower risk of developing cancer and that it is associated with prolonged survival after cancer, independent of stage (21;46;47), and specifically after breast cancer (48), colon cancer (49), and urologic cancer (50). On top of survival advantages, marriage seems to be related to better physical and psychological outcomes after cancer diagnosis (51;52). In a mixed group of cancer patients, unmarried men reported more psychological distress than married men (53). Unmarried men were also found to report more negative thoughts and feelings related to their illness and more disruption in work activities and family relationships than did married

men (54). A higher percentage of unmarried cancer patients reported higher levels of psychological distress, and more negative thoughts and feelings (e.g., reduced self-esteem or body image problems) during active treatment than their married counterparts. Also, single cancer patients experienced less social support and consequently more distress than their married counterparts (55). These findings demonstrate the advantages of being in a committed relationship, especially for people who have to overcome major life events, such as cancer.

Relevance for studying relationship aspects in testicular cancer patients and survivors

The overall quality of life of testicular cancer survivors has been studied before. It appeared that, on the whole, testicular cancer survivors experience a good quality of life, a meaningful life and little long-lasting fatigue (8;56). However, a minority did report low quality of life, and 1 out of 7 men still experienced clinically elevated levels of post-traumatic stress response even years after completion of treatment (57). Besides stress response symptoms, around 15% of long term testicular cancer survivors still experience sexual problems, mostly ejaculatory dysfunction (56;58). Up to 25% of survivors seem to experience fertility problems as well, either due to treatment or to a possible underlying physiological mechanism also responsible for development of the cancer (56). As no relationships were found between objective treatment related aspects (type of treatment and time since completion of treatment) and quality of life or sexual dysfunction, it might be that subjective evaluations are more important determinants of functioning (59). Indeed, it has been found that cancer-related distress best predicted the quality of life of long-term survivors (60).

Shortly after the breakthrough in the treatment of testicular cancer, attention focussed on the psychosocial effects on spouses in this group as well. Several studies reported on relationship satisfaction and the functioning of spouses (61-63). It appeared that the majority of relationships was strengthened after the cancer experience, and spouses even reported increased sexual satisfaction. Unfortunately, results from these studies were based on very small samples (10-34 couples), relatively shortly after completion of treatment, and functioning was studied on a group level. The specific long term effects testicular cancer and its treatment can have on fertility and sexuality are of great importance in an intimate relationship, and can have a large effect on the quality of life of partners. It is therefore relevant to gain insight into the quality of life of spouses in the long term and to explore whether functioning in couples is related.

As testicular cancer is most common in young men, it is likely that many of them are not (yet) in a committed relationship when they are diagnosed. Besides, testicular cancer patients are at significant increased risk for divorce (64). Consequently, some men will develop a relationship with a new partner after completion of treatment. Surprisingly and unfortunately, the effect of relationship status on functioning has not been studied in this specific cancer

population, nor the functioning of couples who developed a relationship after the period of treatment.

Research model

Based on the stress-coping model, Holland and colleagues proposed a psycho-social model that identifies variables that are related to quality of life after a cancer diagnosis (16). Cancer, as the stressful life event, results in measurable characteristics of the event such as type of treatment or a recurrence. Personal and social variables are impacted by the cancer event, and may in turn affect outcome (quality of life). Figure 1 is a representation of this model and summarizes the related variables and relationships that are studied in this thesis.

Outline

This thesis addresses the psychosocial functioning of testicular cancer survivors and their spouses, and possible differences in functioning of survivors according to relationship status. To gain insight into short- and long-term functioning, a large group of men diagnosed and treated over a period of 25 years (1977 – 2003) and their spouses are included.

The general aims of the thesis are to study:

1. the functioning of spouses of testicular cancer patients and survivors
2. correspondence in functioning between survivors and spouses
3. differences in functioning according to relationship status
4. effect of medical, personal and social variables on functioning

Chapter 2 examines the quality of life and stress response symptoms of 259 spouses. A distinction will be made between spouses who were present since time of diagnosis and spouses who developed a relationship with the survivor after his treatment was completed. *Chapter 3* focuses on the marital and sexual satisfaction of couples who were confronted with testicular cancer an average of 9 years earlier. The main aim was to study correspondence between survivors and spouses. Couples who developed a relationship after completion of treatment were included also. The study that is presented in *chapter 4* focuses on the expression of negative emotions. The main research question is whether the expression of emotions of survivors changes due to the experience with cancer and if emotional expression affects the marital satisfaction and distress of the survivor and that of his partner. To gain more insight into adjustment patterns, the quality of life and stress response symptoms of couples facing testicular cancer over the first year after diagnosis is studied in *chapter 5*. Correspondence between patients and spouses was examined, but this time longitudinally during the first year after diagnosis. The last two chapters describe studies that do not include spouses. The focus lies on possible differences in functioning of patients and survivors according to relationship status. *Chapter 6* focuses on social support, self-esteem and mental health by comparing survivors with or without a steady partner, and those with a new part-

ner. *Chapter 7* is a longitudinal prospective study and focuses on changes in sexual functioning and depressive symptoms during the first year after diagnosis and possible differences between patients with or without a partner. Finally, in *chapter 8* an overall discussion of the findings of the preceding studies is presented as well as suggestions for future research and clinical implications.

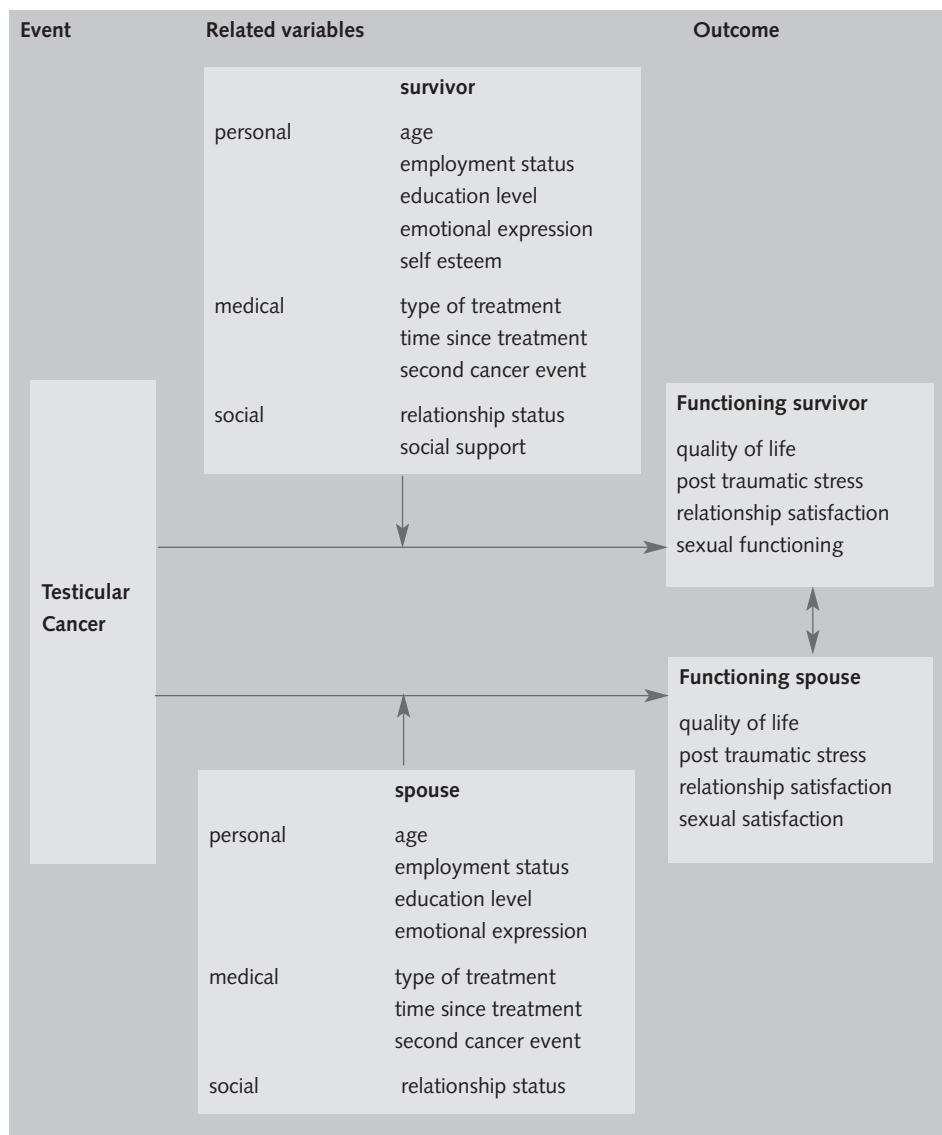


Figure 1 Schematic representation of the variables addressed in the thesis based on the model of research in psycho-oncology (Holland et al. 2002).

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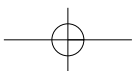
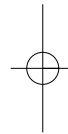
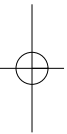
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**chapter 2 quality of life and stress
response symptoms in long-term
and recent spouses of testicular
cancer survivors**

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Introduction

Cancer is most common in elderly people. In men, 75% who develop cancer are 60 years of age or older (1). Testicular cancer in contrast, mainly affects young men of between 15 and 40 years; the highest prevalence lies at around 30 years of age. This disease strikes men in an important phase of life, which is often characterised by the start of a career and/or a family. Since 1980, the survival chances of testicular patients are good, with a cure rate up to 90%, owing to the availability of cisplatin-based polychemotherapy (2). Increasing numbers of men are therefore becoming testicular cancer survivors.

Cancer patients are not isolated in their suffering. Confrontation with the diagnosis and treatment also has a heavy impact on family and spousal relationships (3-7). Studies have shown that the spouses of cancer patients have more psychological problems than spouses of healthy subjects. The percentage of spouses that report problems at a clinically increased level varies between 18% and 30% (5;8-10). Other studies have shown that when a cancer patient reports a high level of distress, his or her spouse is also found to have a high level of distress (3;11;12). Similarly, when the patient has psychological adjustment problems, the same is true for the spouse (10;12;13).

These studies on the spouses of cancer patients have several shortcomings. In the populations of spouses in these studies there was an over-representation of male spouses of breast cancer patients, thus not providing insight into the reactions of female spouses. In addition, the studies were aimed at the spouses of patients with different types of cancer. The studies were conducted during treatment or shortly after diagnosis (6 - 12 months), thus no information was obtained about long-term consequences. Moreover, the studies only included spouses who were married or already had a steady relationship with the patient at the time of diagnosis.

Only four studies reported the effects on spouses and the close family of men with testicular cancer. One research group studied patients with different diagnoses; the testicular cancer survivors and their spouses formed only 14% of the total study group (3). Another study had a qualitative and explorative design (14). Hannah and colleagues studied marital and sexual functioning, whereas Gritz and focused on psychological functioning, i.e. feelings of anxiety and depression. The latter study showed that the level of depression in the patient and spouse were within the normal range and that there was a strong relationship between the emotional status of the TCS and that of his spouse. These four studies that aimed specifically at testicular cancer patients and their spouses had small study populations (n=10-34).

The present retrospective study was conducted to gain greater insight into the global functioning of spouses of TC survivors. Information was obtained on their general quality of life (QoL) on a physical, psychological and social level. In addition, we investigated the extent to which confrontation with cancer was still playing a role in their daily lives by measuring stress response symptoms. As testicular cancer mainly affects young men, part of this group had not yet started a steady relationship at time of diagnosis. Therefore spouses who developed

a relationship after treatment was completed were also included in this study. The following questions formed the central theme of the study:

- (1) Do spouses of testicular cancer survivors differ in QoL from a reference group of women?
- (2) Do spouses who were present during the diagnosis and treatment differ in QoL and stress response from spouses who started a relationship with a TCS after the completion of treatment?
- (3) Do QoL and stress response correspond in testicular cancer survivors and his spouse?
- (4) Are QoL and the stress response of spouses related to treatment related aspects (time since treatment completion, extent of treatment and a second cancer event)?

Patients and methods

Procedure

All men treated for testicular cancer between 1977 and 2002 at the Groningen University Hospital in the Netherlands were approached in writing and invited to take part in a questionnaire survey. Exclusion criteria were previous psychiatric history, diagnosis within the past six months and age younger than 18 years.

A total of 702 men received written information explaining the aim of the study and an invitation to participate. An invitation for the spouse to take part was also enclosed. Informed consent forms and a prepaid return envelope were provided. Male spouses and spouses younger than 18 years were excluded. The study was approved by the Medical Ethics Committee of the Groningen University Hospital.

Participants

A total of 354 men (50%) agreed to participate in the study; 299 (84%) were married or cohabiting. It appeared that one testicular cancer survivor had a spouse younger than 18 years and three testicular cancer survivors had a male spouse. A total of 259 out of the 295 eligible spouses (88%) agreed to participate. Thus, 259 couples, i.e. testicular cancer survivors and their spouses, participated in the study; 219 (85%) of the couples had a steady relationship during the diagnosis and treatment (couples during testicular cancer), while 40 couples (15%) had started a relationship after completion of treatment (couples after testicular cancer). No information was available about the spouses who did not wish to participate, because they were invited anonymously via the testicular cancer survivors. Analyses with data from the hospital database showed that non-responding testicular cancer survivors did not differ from responders in age, marital status, age at time of diagnosis or type of treatment they received.

Measurements

Testicular cancer survivors and spouses filled in the same questionnaire. Data were obtained on various demographic aspects: age, type of relationship (married or cohabiting), duration of the relationship, presence of children, employment status and education level. Employ-

ment status could be indicated as full time, part-time, housekeeping, student, unemployed, unable to work, or retired. Education level was measured on a seven-point scale: primary school (1), lower vocational degree (2), lower secondary (3), middle secondary (4), high secondary (5), higher vocational (6) university (7). Information was also obtained from the testicular cancer survivors on disease and treatment aspects: date of completion of treatment, type of treatment and the occurrence of tumor relapse or a second primary malignancy. Type of treatment could comprise: orchiectomy (removal of the affected testicle) alone, orchiectomy with retroperitoneal lymph node dissection (RPLND), orchiectomy and chemotherapy, orchiectomy and chemotherapy and resection of residual retroperitoneal tumor mass (RRRTM) or orchiectomy and radiotherapy.

Quality of Life was measured with the RAND-36 (15), a questionnaire identical to the Short Form (SF)-36 (16). The RAND-36 measures generic QoL and comprises three dimensions. The first-dimension assesses functional status and consists of four subscales: physical functioning (10 items), social functioning (2 items), role limitations due to a physical problem (4 items) and role limitations due to an emotional problem (3 items). The second-dimension measures well-being and consists of three subscales: mental health (5 items), vitality (4 items) and pain (2 items). The third-dimension includes a generic evaluation of health status and consists of 2 subscales: general health perception (5 items) and health change (1 item). After recoding and transformation, scores on the subscales could range from 0 to 100. Higher scores indicate a better QoL. The internal consistency of these subscales for spouses was good (alpha ranged from 0.75 - 0.92), while for testicular cancer survivors it was moderate to good (alpha ranged from 0.67 - 0.91).

Stress response symptoms were measured with the Dutch version of the Impact of Event Scale (17;18). This scale makes an inventory of the extent to which a subject is currently occupied with the coping process after a major event, and is often used in studies on cancer patients (19). With this questionnaire, information was obtained about the degree to which confrontation with TC was influencing the current daily life of the respondent. Two dimensions were measured with 15 items: intrusion (intrusively experienced ideas, images, feelings or bad dreams about the event) via 7 items with answer categories ranging from never (0) to often (5) and avoidance of unpleasant feelings or memories of the event via 8 items with the same answer categories. Total scores of more than 26 formed a strong indication of severe stress response symptoms, for which psychological help is recommended. The internal consistency of this questionnaire was good for the spouses (alpha = 0.92) and good for the testicular cancer survivors (alpha = 0.85).

Statistics

The database consisted of matched pairs of spouses and testicular cancer survivors. Paired *t*-tests and Chi-square tests were applied to investigate whether there were any sociodemographic differences between spouses and testicular cancer survivors. Separate analyses were performed on 'spouses during testicular cancer' and on 'spouses after testicular cancer'.

Independent *t*-tests and a Chi-square test were applied to investigate whether there were any sociodemographic differences between the two spousal groups. To compare the spouses to a reference group of women, reference scores were used from the Dutch manual for the RAND-36. These comprised the mean scores from a group of 691 non-selected women from a random sample of 1063 persons aged 18 years and older from the population register of a municipality in the north of The Netherlands (no. of inhabitants = 108,000). The mean age of the persons in the total random sample was 44.1 years (range 18-89 years) (15). To investigate differences between the spouses and the reference group, independent *t*-tests were performed. Analysis of Covariance (ANCOVA) was used to test for differences in QoL and stress response between the two groups of spouses.

A partial correlation analysis was performed to investigate the relationship between QoL and stress response in the testicular cancer survivors and their spouses. To test differences between spouses and testicular cancer survivors, a paired *t*-test was used, because scores within a couple were not independent.

To investigate the effect of treatment related variables dichotomous variables were created for type of treatment and for a relapse, second diagnosis of TC or a second other cancer diagnosis. Type of treatment was divided into 0 = 'surgical treatment' (orchietomy and orchietomy plus RPLND) and 1 = 'combined treatment' (orchietomy plus chemotherapy, or plus chemotherapy and RRRTM or plus radiotherapy). Occurrence of a second cancer event was divided into 0 = 'no' and 1 = 'yes'. Furthermore, the testicular cancer survivors were divided into five groups according to the type of treatment received: orchietomy alone (1), orchietomy + RPLND (2), orchietomy + chemotherapy (3), orchietomy + chemotherapy + RRRTM (4) and orchietomy + radiotherapy (5). An ANCOVA (for the 2 treatment categories and second cancer event) and a Scheffé-test (for the 5 categories) was conducted to investigate differences in QoL and stress response between the two spousal groups. To investigate the influence of time since completion of treatment, a partial correlation analysis was conducted.

Results

Descriptives

The spouses had an average age of 43.1 years (range 21-75 years) and were significantly younger than the testicular cancer survivors (mean 45.3 years; range 21-78 years; $t = 10.3$, $p < .0001$). The average education level of the spouses was 3.9, which was significantly lower than that of the testicular cancer survivors (mean 4.2; $t = 2.7$, $p < .01$). The spouses and testicular cancer survivors had been together, married or cohabiting, for an average of 18.9 years (range 0.5-50 years). Mean duration since the completion of treatment was 9.3 years, ranging from 0.5 to 23.8 years. Relapse, a second testicular tumour or a second primary malignancy occurred in 10% of the testicular cancer survivors (Table 1).

In the total group of spouses, 15% ($n=40$) had begun a relationship with the TCS since the

Table 1 Descriptives of spouses and testicular cancer survivors

	Spouses		Testicular Cancer Survivors	
Age				
Mean (SD)	43.1	(11.5)	45.3	(11.4)
Range	21-75		21-78	
Education level (range 1-7)				
Mean (SD)	3.9	(1.6)	4.2	(1.7)
Relationship status N, %				
Married	247	95%		
Cohabiting	12	5%		
Duration relationship				
Mean (SD)	18.9	(12.3)		
Range	0.5-50			
Type of treatment N, %				
Orchiectomy			68	26%
Orchiectomy and RPLND			20	8%
Orchiectomy and chemotherapy			45	17%
Orchiectomy, chemotherapy and RRRTM			77	30%
Orchiectomy and radiotherapy			49	19%
Time since completion of treatment				
Mean (SD)			9.3	(6.5)
Range			0.5-23.8	
Relapse, second cancer N, %				
Tumour relapse			11	4%
Second testicular cancer			8	3%
Second other cancer			7	3%
No			233	90%

RPLND, retroperitoneal lymph node dissection; RRRTM, resection of residual retroperitoneal tumour mass.

completion of treatment. Spouses during TC were an average of 44.3 years of age (SD = 11.6), while spouses after TC were an average of 36.7 years of age (SD = 8.6). This difference in age was significant ($t = -3.9, p < .0001$). Mean duration of the relationship with a TCS was 20.9 years (SD=12.1) for the spouses during TC and 7.4 years (SD=5.5) for the spouses

after TC. This difference was also significant ($t = -6.7, p < .0001$). There were no other sociodemographic differences between the two spousal groups. Chi-square tests showed that a second primary tumour and/or tumour relapse occurred with equal frequency in the testicular cancer survivors of spouses after TC and spouses during TC. Because 'spouses during testicular cancer' were older than 'spouses after testicular cancer' and they had a relationship of longer duration, age was controlled for in all the analyses. We did not control for the duration of the relationship, because the correlation between age and duration of the relationship was 0.90 ($p = .0001$).

Differences in Quality of Life between spouses and a reference group

QoL of the two spousal groups was compared to a reference group of women. An independent t -test showed that spouses during TC had better physical functioning ($t = 4.3, p < .001$), fewer role limitations due to physical problems ($t = 3.6, p < .001$) and less pain ($t = 4.1, p < .001$) than a reference group of women. However, spouses during testicular cancer also reported poorer social functioning ($t = 2.1, p < .05$).

In common with spouses during testicular cancer, spouses after testicular cancer reported better physical functioning ($t = 3.6, p < .001$) than the reference group. However, in contrast with spouses during testicular cancer, spouses after testicular cancer reported more role limitations due to emotional problems ($t = -2.21, p < .05$), poorer mental health ($t = -2.0, p < .05$) and less vitality ($t = -2.6, p < .05$) than the reference group (Table 2).

Differences in QoL and stress response between spouses during testicular cancer and spouses after testicular cancer

QoL. An ANCOVA (with covariate age) showed that the spouses during testicular cancer had fewer role limitations due to physical problems ($F = 4.9, p < .05$), fewer role limitations due to emotional problems ($F = 4.7, p < .05$), better mental health ($F = 4.9, p < .05$) and more vitality ($F = 4.9, p < .05$) than the spouses after testicular cancer (Table 2).

Stress response. An ANCOVA (with covariate age) showed that spouses during testicular cancer reported more intrusion ($F = 4.2, p < .05$) and more avoidance ($F = 5.9, p < .05$) than spouses after testicular cancer and also reported more total stress response symptoms than spouses after TC ($F = 6.0, p < .05$) (Table 3). In the group of spouses during testicular cancer, 14% ($N = 30$) had a total score above the clinical cut-off point of 26, compared to 0% in the spouses after testicular cancer.

Quality of life and stress response in spouses and testicular cancer survivors

QoL. A partial correlation analysis controlled for age, education level and positive life events showed only two significant correlations. The level of role limitations due to emotional problems ($r = .22, p < .001$) and mental health ($r = .14, p < .05$) in spouses during testicular cancer were significantly correlated with those of the testicular cancer survivors. A paired t -test

Table 2 Descriptives of QoL subscales for spouses during testicular cancer, spouses after testicular cancer and a reference group

	Spouses during testicular cancer		Spouses after testicular cancer		Reference group	
	Mean (SD)		Mean (SD)		Mean (SD)	
Physical functioning	87.7	(19.6)	91.1	(14.3)	80.7 ^{ooo xxx}	(23.6)
Social functioning	83.0	(22.5)	78.8	(23.2)	86.1 ^o	(20.9)
Role limitations-physical problem	87.6	(29.3)	79.4 ⁺	(35.3)	78.3 ^{ooo}	(36.5)
Role limitations-emotional problem	83.6	(32.9)	68.3 ⁺	(42.7)	82.5 ^x	(33.5)
Mental health	76.1	(15.2)	68.7 ⁺	(21.7)	75.5 ^x	(18.9)
Vitality	65.8	(17.3)	57.1 ⁺	(22.3)	66.3 ^x	(19.6)
Pain	86.6	(19.6)	85.8	(20.3)	80.0 ^{ooo}	(25.4)
General health perception	73.4	(17.9)	74.1	(18.1)	71.5	(21.8)
Health change	51.7	(18.0)	51.3	(15.9)	53.4	(19.6)

Comparison spouses during testicular cancer vs spouses after testicular cancer: + = $p < .05$

Comparison spouses during testicular cancer vs reference group: o = $p < .05$, oo = $p < .01$, ooo = $p < .001$

Comparison spouses after testicular cancer vs reference group: x = $p < .05$, xx = $p < .01$, xxx = $p < .001$

showed one difference: spouses during testicular cancer reported better general health than the testicular cancer survivors ($t = -2.4$, $p < .05$).

No significant correlations or differences were found on any of the QoL subscales between spouses after testicular cancer and the testicular cancer survivors.

Stress response. Partial correlation analysis controlled for age and education level (since testicular cancer survivors and spouses differed on these aspects) showed a significant correlation between the stress response symptom scores of spouses during testicular cancer and testicular cancer survivors on the two subscales intrusion ($r = .25$, $p < .0001$) and avoidance ($r = .19$, $p < .01$), and regarding the total score ($r = .24$, $p < .001$).

A paired t -test revealed that spouses during testicular cancer had significantly higher scores than testicular cancer survivors on the subscale intrusion ($t = -2.8$, $p < .01$) and the total score ($t = -2.3$, $p < .05$). No significant difference was found for the subscale avoidance behaviour (Table 3). The level of stress response symptoms in spouses during testicular cancer and testicular cancer survivors was correlated, although the spouses reported more symptoms than the testicular cancer survivors. No significant correlations were found between the scores of spouses after testicular cancer and testicular cancer survivors on intrusion, avoidance and total stress response symptoms.

Table 3 Descriptives of stress response of spouses during testicular cancer, spouses after testicular cancer and testicular cancer survivors

	Spouses during testicular cancer		Spouses after testicular cancer		Testicular cancer survivors	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
Intrusion (Possible range 0-35)	5.3	6.5	3.3 ⁺	4.3	3.8 [*]	5.3
Avoidance (Possible range 0-40)	4.0	6.4	1.6 ⁺	2.6	3.5	5.8
Total (Possible range 0-75)	10.9	14.0	5.6 ⁺	7.4	8.3 ^{**}	10.9

Comparison spouses during testicular cancer vs spouses after testicular cancer: + = $p < .05$

Comparison spouses during testicular cancer vs testicular cancer survivors: * = $p < .05$, ** = $p < .01$

Treatment related aspects and QoL and stress response of spouses

Time since completion of treatment. No significant correlations were found between the interval since completion of treatment and the various QoL domains. This was the case for both spouses during testicular cancer and spouses after testicular cancer. Similarly, no significant correlations were found between the interval since completion of treatment and stress response symptoms in spouses during testicular cancer or in spouses after testicular cancer.

Type of treatment. Spouses of men who underwent surgery alone were significantly younger than spouses of men who received combined treatment ($F=4.6$, $p < .05$); no other sociodemographic differences in these groups were found. An ANCOVA (with covariate age) showed no effect of extent of treatment on the QoL domains. This was found to be the case in both spousal groups. An ANCOVA (with covariate age) did show differences in stress response symptoms. Spouses during testicular cancer of men who underwent surgery alone ($n=74$) reported significantly fewer symptoms of intrusion ($F=6.7$, $p < .01$) and less avoidance ($F=5.1$, $p < .05$) than spouses during testicular cancer of men who had received combined treatment ($n=145$). Consequently there was a difference in the total scores on stress response symptoms between these two groups ($F=8.1$, $p < .01$). In spouses after testicular cancer, no differences were found in stress response symptoms when the extent of treatment was considered (Table 4).

Within both spousal groups no differences were found in the subscales of QoL or in stress response symptoms when treatment was classified into 5 groups and analysed using a Scheffé-test.

Table 4 Descriptives of stress response for different types of treatment

	Surgical treatment (Orchiectomy +/- RPLND)		Combined treatment (Orchiectomy + RT or CT +/- RPLND)	
	Mean	(SD)	Mean	(SD)
Spouses during testicular cancer	N = 74		N = 145	
Intrusion	3.7	(5.7)	6.1 ⁺⁺	(6.8)
Avoidance	2.7	(4.8)	4.7 ⁺	(6.9)
Total	7.2	(11.3)	12.7 ⁺⁺	(14.9)
Spouses after testicular cancer	N = 14		N = 26	
Intrusion	4.2	(4.9)	2.9	(3.9)
Avoidance	1.8	(2.5)	1.6	(2.8)
Total	6.6	(8.1)	5.3	(7.3)

Comparison surgical treatment vs combined treatment: += p<.05, ++= p<.05
RT, radiotherapy; CT chemotherapy

Second cancer event. Spouses during testicular cancer whose husband experienced a second cancer event were older ($t = -2.2$, $p < .01$) than those whose husband did not have a second event. ANCOVA (covariate age) did not show any differences in QoL or stress response between these groups. For the group of spouses after testicular cancer the sample of a second cancer event was too small to analyse ($n=4$).

Discussion

The aim of this study was to gain insight into the quality of life of spouses of testicular cancer survivors and into stress response symptoms after cancer. It was particularly surprising that there was such a marked difference in QoL between the spouses who had been in a steady relationship with the patient throughout the period of illness and had thus experienced the whole diagnosis and treatment process (spouses during testicular cancer) and the QoL of the spouses who had begun a relationship with a testicular cancer survivor more recently, after the completion of treatment (spouses after testicular cancer). Spouses during testicular cancer had fewer physical problems and were functioning better with regard to several psychological aspects: they had fewer emotional problems, better mental health and more vitality than spouses after testicular cancer.

In contrast, spouses during testicular cancer did report more total stress response symptoms, more avoidance behaviour concerning feelings and memories related to confrontation with their spouse's testicular cancer and more intrusive thoughts. Nevertheless, although a differ-

ence was found in stress response between these two groups of spouses, it should be realised that even in spouses during testicular cancer, the level of stress response was low. However, a small group of spouses during testicular cancer (14%), were experiencing a stress response level above the cut-off score of 26 points and psychological counselling is recommended in such cases (18).

In this study, the mean QoL scores of the spouses were compared to those from a reference group (15). The results emphasised the above-described differences between the two groups of spouses. Spouses during testicular cancer had better physical QoL than the reference group of women. They experienced better physical functioning, fewer role limitations due to physical problems and less pain. This disagrees with the finding that women tend to develop somatic complaints more quickly than men after negative life events (20). It is possible that owing to their experience, these spouses were less likely to regard their physical complaints as distressing. They had a different frame of reference: a husband who has won the fight against cancer. Apparently, these women judge their own health and physical functioning to be better than that of women who have not had such an experience.

Spouses after testicular cancer also judged their physical functioning to be better than that of the reference group, but they had more role limitations due to emotional problems, poorer mental health and less vitality than the reference group of women.

Earlier research into the effects of cancer that included the spouses always focused on spouses who were married or involved in a steady relationship with the patient since before the diagnosis. The present study, which also included recent spouses, showed that these 'spouses after testicular cancer' were distinctly different from the spouses during testicular cancer. It is possible that this is related to spouse selection: the choices and wishes of the testicular cancer survivors themselves when they seek a partner that fits in their lifestyle (21).

QoL and stress response symptoms of 'spouses after testicular cancer' were not significantly related to those of the testicular cancer survivors. Within couples of 'spouses during testicular cancer' and testicular cancer survivors, it appeared that if one was suffering from more role limitations due to emotional problems and poorer mental health, then the other was too. Furthermore, spouses during testicular cancer had better general health than the testicular cancer survivors, which is highly credible, because men who have been cured of testicular cancer often develop complaints in the long-term, such as fatigue, cardiovascular disorders and tingling or painful fingers (22). Earlier studies showed inconsistent results regarding correlation in the level of distress between spouse and patient. Sometimes there seemed to be dyadic adjustment, whereas in other work, no relationship could be demonstrated (23).

Stress response symptoms were also related in spouses during testicular cancer and testicular cancer survivors. Within couples of spouses during testicular cancer and testicular cancer survivors, it appeared that if one had intrusions about the experience with testicular cancer and was avoiding thinking about it, then the other one was, too. Spouses were experiencing a higher stress response level than the survivors. This is in agreement with other studies that

showed that spouses were sometimes experiencing more distress than the cancer patients (24;25). Particularly female spouses react strongly to a diagnosis of cancer (23). In our group that comprised female spouses only, the reaction of the spouse was also stronger than that of the TCS. However, this was valid for stress response symptoms, but not for QoL. An explanation might lie in the different way the questions were formulated. Questions that measured QoL had a generic design, whereas the questions on stress response symptoms were formulated specifically for a confrontation with testicular cancer.

Psychosocial adjustment of cancer patients and their spouses has been studied previously by, for example, Northouse and colleagues (26). Their research showed that patients and spouses have different adjustment patterns. Patients and spouses reported decreases in family functioning and social support, but improvements in emotional distress over time. Unfortunately, this was only studied during the first year after surgery and not in the longer-term. In the group of spouses who took part in the present study, the time since completion of treatment varied widely. It was found that the reactions of spouses whose event had occurred longer ago was no different from that of spouses whose event was much more recent. It is possible that these spouses of testicular cancer survivors have short-term effects in adjustment: after a certain interval, differences in functioning are less affected by the time elapsed, but possibly more affected by the personality of the spouses or other events. This agrees with the findings reported by Keller and colleagues (10) who indicated that in the case of a favourable course of a disease, emotional well-being of the spouses gradually improves over the first few months after diagnosis: recovery to the former level of psychological functioning seems to occur as time passes.

The type of treatment received by the testicular cancer survivors might affect our data. More extensive treatment might have greater negative consequences. It appeared this was not the case for QoL, but it was for the level of stress response. Spouses of men who received surgery alone (orchiectomy, or orchiectomy plus RPLND) had fewer stress response symptoms than spouses of men who received combined treatment (surgery plus chemotherapy or radiotherapy). The greater the extent of treatment, the stronger the stress response in the spouse. This applied solely to the spouses who had been present throughout the diagnosis and treatment process. A possible explanation lies in the indication for surgery and the consequences of the type of treatment on the spouse. Most men who receive surgery alone have early stage disease with an excellent prognosis, and they recover rapidly after treatment. In contrast, men who receive adjuvant chemotherapy, radiotherapy and sometimes even a second abdominal operation (RRRTM) have more advanced stage disease, may have a poorer prognosis, are away from home longer because of the intensive treatment, and may experience unpleasant side-effects or consequences from the treatment.

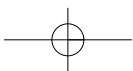
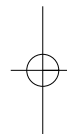
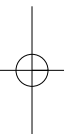
In conclusion, spouses who were present throughout the diagnosis and treatment process had better physical QoL than the average woman. Stress response levels in 'spouses during

testicular cancer' were low and related to the stress response level of the testicular cancer survivor and to the extent of treatment he had received. However, these spouses, even in the longer-term after the completion of treatment, were experiencing more stress response symptoms than the testicular cancer survivors. Furthermore, there were important differences between spouses who were present throughout the diagnosis and treatment process and spouses who had begun a relationship with a TCS more recently, after the completion of treatment. Spouses after testicular cancer reported poorer psychological QoL, both in comparison with spouses during testicular cancer and a reference group of women. Research into the processes of building up a relationship after surviving cancer might provide more insight into these results.

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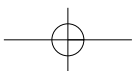
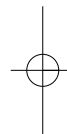
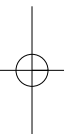
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chapter 3 marital and sexual satisfaction in testicular cancer survivors and their spouses

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Introduction

Testicular cancer (TC) mainly affects young men aged between 15 and 40 years; the highest incidence lies around 30 years. Since 1980, survival rates in TC patients have been excellent (up to 90%), owing to the availability of cisplatin-based polychemotherapy (25). Consequently, increasing numbers of these patients are going through life as TC survivors (TCSs). Having cancer and surviving it can strongly affect close relationships, especially the relationship with the spouse. Marital satisfaction of cancer patients and their spouses has been studied fairly extensively. It appears that only a small proportion of couples have difficulties adjusting to the stress of cancer after treatment is completed (18;21). However, most research concerns women with cancer and their partners. It appears that female spouses are at risk of developing psychological problems when confronted with their husband's cancer (9;21). Little research has been done into marital satisfaction of especially men with cancer and their female partners, and only two studies have addressed this issue in TCSs and their spouses. These two studies (on the same group of TCSs and spouses) showed that couples felt the relationship became more tightly bonded and stronger following the confrontation with TC (6;10). However, it should be noted that the results were based on a fairly small sample ($n=34$) and on a group survivors who had completed treatment an average of 4 years prior to the assessment, thus not showing insight into long-term adjustment.

Among other aspects, the sexual relationship between partners plays an important role in marriage. Studies on married couples showed that sexual satisfaction influences marital satisfaction (4;15). Schover et al. studied sexual and marital relationships in two groups of TCSs. They found that the ability to function sexually was a crucial factor in marital happiness (23) and that marital happiness was highly correlated with sexual satisfaction (22). Unfortunately, no information was collected from the spouses.

Several studies focused specifically on sexual functioning after testicular cancer, because this type of cancer involves an organ associated with sexuality and occurs in a phase of life in which sexuality is of great importance (5;14;20). TCSs reported several physical sexual problems such as erectile dysfunction, ejaculatory failure and orgasmic problems. Percentages of functional problems vary between studies. The impact of different treatment modalities, i.e. surgery, radiotherapy or chemotherapy, can be the cause of these physical sexual dysfunctions (26;27). However, psychological factors also play an important role in the sexuality of TCSs, and they are known to influence more subjective aspects such as sexual desire, sexual activity and sexual satisfaction (5;14).

If a TCS experiences problems with sexual functioning, this can not only affect his own sexual satisfaction but also that of his spouse, and it may even affect the marital satisfaction of both partners. It is important to establish whether spouses also experience changes or problems in sexuality so that good information can be given to both patient and spouse. Although attention has been paid to sexual functioning in TCSs themselves, very little research has been done into the sexual satisfaction of their partners. Two reports have been

published on sexual functioning, in the same group of 34 TCSs and spouses mentioned above (7;10). TCSs and their spouses reported a decrease in sexual frequency since the illness and treatment. In 30% of the TCSs, this meant a decrease in sexual satisfaction whereas in almost 50% of spouses, this meant an increase in sexual satisfaction. The results of this evaluation of the spouses may be the result of increased intimacy between the couple, but other factors may be involved.

In summary, TC survivors have been identified as a group at risk for sexual dysfunction. Sexual problems can also affect the spouse's evaluation of marital and sexual satisfaction. Marital satisfaction seems to be good in TCSs and their spouses, but the two studies that addressed these issues focused on a small group over a small range of time since completion of treatment.

The goal of the current study was to investigate the level of marital and sexual satisfaction in both TCSs and their spouses. The study population comprised a large group of long-term TCSs and their spouses. As testicular cancer mainly strikes young men, part of this group had not yet started a steady relationship at time of diagnosis. It may be that couples who did not share the experience of the illness together evaluate their marital and sexual relationships differently from couples who already had a steady relationship at time of diagnosis. Therefore couples who developed a relationship after treatment was completed were also included in this study (couples after TC).

The following questions formed the central theme of the study: (1) Do couples during TC differ in marital and sexual satisfaction from couples after TC? (2) Do survivors and their spouses differ in marital and sexual satisfaction from a reference group of Dutch couples and from each other? (3) Are marital and sexual satisfaction of survivors related to those of spouses? (4) Are treatment-related variables associated with marital and sexual satisfaction in survivors and spouses? (5) Do couples during TC feel that the relationship has changed due to the experience with testicular cancer? (6) Do couples after TC feel that the TCS's experience with testicular cancer has affected their relationship?

Methods

Procedure

All the men treated for testicular cancer between 1977 and 2002 at the University Medical Centre Groningen in the Netherlands were approached in writing and invited to take part in a questionnaire survey. Exclusion criteria were diagnosis within the past 6 months and age younger than 18 years. A total of 702 men received written information explaining the aim of the study and an invitation to participate. An invitation for the partner to take part was also enclosed. Female partners older than 18 years were included. Informed consent forms and a prepaid return envelope were provided. The study was approved by the Medical Ethics Committee of the University Medical Centre Groningen.

Respondents

A total of 354 men (50%) agreed to participate in the study; 299 (84%) had a steady relationship. It appeared that four partners did not meet the inclusion criterion. A total of 259 out of the 295 eligible partners (88%) agreed to participate. Thus, 259 couples, i.e. TC survivors and their spouses, participated in the study; 219 (85%) of the couples had a steady relationship during diagnosis and treatment (couples during TC) while 40 couples (15%) had started a relationship after completion of treatment (couples after TC). No information was available about the partners who did not wish to participate because they were invited anonymously. Analyses with data from the hospital database showed that nonresponding TCSs did not differ from responders in age, marital status, age at time of diagnosis or type of treatment received.

Questionnaire

TCSs and spouses filled in the same questionnaire. Data were obtained on various demographic aspects: age, duration of relationship, presence of children, employment status and education level. Employment status could be indicated as full time, part time, housekeeping, student, unemployed, unable to work, or retired. Highest education level completed was measured on a 7-point scale: primary school (1), lower vocational degree (2), lower secondary (3), middle secondary (4), high secondary (5), higher vocational (6) and university (7). Information was also obtained from the TCSs on disease and treatment aspects: date of completion of treatment, type of treatment and occurrence of tumor relapse or a second primary malignancy. Type of treatment could comprise: orchiectomy (removal of the affected testicle) alone, orchiectomy with retroperitoneal lymph node dissection (RPLND), orchiectomy and chemotherapy, orchiectomy and chemotherapy and resection of residual retroperitoneal tumor mass (RRRTM) or orchiectomy and radiotherapy.

Marital and sexual satisfaction. The Dutch version of the Maudsley Marital Questionnaire (MMQ) was used to measure marital satisfaction (1;11). The MMQ defines marital satisfaction as the subjective evaluation of the emotional connection and the sexual relationship with the partner. Two subscales of the MMQ were used: marital satisfaction (ten items) and sexual satisfaction (five items). Each item was measured on a 9-point scale (0-8). Respondents were asked to indicate which point on the scale best described their situation over the previous 2 weeks. Items in each subscale were summed. Scores on the marital satisfaction subscale could range from 0 to 80 and on the sexual satisfaction subscale from 0 to 40, with a higher score indicating less satisfaction. Mean scores on the MMQ from a random sample of 125 volunteer Dutch couples were used for comparison purposes (1). Mean age was 42.5 years (SD=11.23) and they had been married an average of 17.8 years (SD=10.2), which is comparable to the current study population. A cutoff score of ≥ 20 on the marital satisfaction subscale was used to identify individuals who experience marital dissatisfaction comparable

to couples referred for marital counselling, which indicated marital problems. An earlier study showed that approximately 5% of a sample of 64 married couples was experiencing marital problems that resulted in a score above the cutoff point (2;11). Previous research has shown that the MMQ is a reliable and valid instrument for the measurement of marital quality (1;3;11). Reliability of the MMQ in the present study was good. Cronbach's alpha for TCSs for marital satisfaction was 0.82 and for spouses 0.89. Cronbach's alpha for sexual satisfaction for TCSs was 0.80 and for spouses 0.76.

Self constructed questions were added to the MMQ. TCSs and spouses who had a steady relationship at time of diagnosis were asked: "Do you think that your relationship has changed due to your experience with TC?" Answers could be given on a 5-point scale, varying from "Yes, I think the relationship has improved a lot" (1) to "Yes, I think the relationship has deteriorated a lot" (5). TCSs and spouses who developed a relationship after treatment were asked a different question: "Is the fact that you/your partner had TC affecting your relationship at present?" Answers could be given on a 5-point scale, varying from "Yes, a great deal" (1) to "No" (5).

Statistical analyses

The database consisted of matched pairs of TCSs and spouses. ANCOVA (analyses of covariance) were computed to compare couples during TC to couples after TC while controlling for differences in sociodemographic characteristics between the two groups. Independent *t*-tests were performed to compare marital and sexual satisfaction of TCSs and spouses to those of men and women from the reference group. Effect sizes were calculated using Cohen's *d* to assess the clinical significance of differences found. Effect sizes smaller than .20 indicated a trivial difference, effect sizes between 0.20 and 0.50 indicate a small difference, those between 0.50 and 0.80 a moderate difference and those greater than 0.80 can be seen as clinically important differences (19). Partial correlations were computed to examine relationships between TCSs and their spouses regarding marital and sexual satisfaction, controlling for differences in sociodemographic characteristics between partners.

As data obtained from partners were not independent, paired *t*-tests were performed to analyze differences in mean scores between TCSs and spouses. The cutoffscore was used to identify TCSs and spouses who were experiencing marital problems.

To examine treatment-related variables in relation with marital and sexual satisfaction, correlation analyses (for time since completion of treatment), independent *t*-tests (type of treatment in two categories and experience of a second cancer event) and a Scheffé test (for type of treatment in five categories) were conducted.

Dichotomous variables were created for type of treatment and for a relapse, second diagnosis of TC or a second other cancer diagnosis. Type of treatment was divided into 0 = "surgical treatment" (orchiectomy and orchiectomy plus RPLND) and 1 = "combined treatment" (orchiectomy plus chemotherapy, or plus chemotherapy and RRRTM or plus radiotherapy). Occurrence of a second cancer event was divided into 0 = "no" and 1 = "yes".

Correlations were computed for both groups of couples between responses to the self-constructed questions and level of marital and sexual satisfaction.

Results

Preliminary results

The two couple groups (during and after TC) differed on several sociodemographic characteristics. TCSs and spouses of couples during TC were older ($t=1.9$, $p<0.001$ and $t = 3.8$, $p<0.0001$ respectively), their relationship was of longer duration ($t =6.7$, $p<0.000$), more of them had children ($\chi^2=31.7$, $p<0.0001$) and time since completion of treatment was shorter ($t =3.0$, $p<0.01$) than in the TCSs and spouses of couples after TC. As the duration of the relationship was highly correlated with the age of TCSs and spouses ($r=0.89$, $p<0.0001$ and $r=0.90$, $p<0.0001$ respectively), age was not included as a covariate in the analyses.

Descriptives

TCSs were significantly older than spouses ($t =10.3$, $p<0.0001$). TCSs had a higher education level ($t =2.7$, $p<0.01$) and more of them had a job ($\chi^2=20.4$, $p=.0001$) than spouses. In TCSs, 192 had children and 193 of the spouses had children. Three TCSs had no children of their own, but their spouse had children. Two spouses did not have children of their own, but the TCS did (Table 1).

Do couples during TC differ in marital and sexual satisfaction from couples after TC?

ANCOVA (controlling for age, time since completion of treatment and the presence of children) showed that TCSs who had a steady relationship at time of diagnosis reported more sexual satisfaction than TCSs who started a relationship after completion of treatment ($F=7.4$, $p<0.01$); there were no differences in their marital satisfaction. Effect size of the difference in sexual satisfaction was -0.08 (95% confidence interval of the difference -0.42 to -0.26) indicating that the difference was clinically marginally relevant. ANCOVA showed no differences in marital and sexual satisfaction between the spouses during TC and the spouses after TC (Table 2).

Do survivors and their spouses differ in marital and sexual satisfaction from a reference group?

Couples during TC: Independent t -tests showed that TCSs as well as their spouses experienced similar marital satisfaction to that reported by the reference group. TCSs who had a steady relationship during TC reported less sexual satisfaction than men in the reference group ($t =2.9$, $p<0.01$). Effect size of the difference in sexual satisfaction was 0.30 (95% confidence interval of the difference $0.07 - 0.52$) indicating that the clinical relevance was small. Spouses during TC reported less sexual satisfaction than women in the reference group ($t =2.9$, $p<0.01$). Effect size was 0.30 (95% confidence interval of the difference $.08 - .53$) indicating a small difference.

Table 1 Descriptives

	Testicular Cancer Survivors		Spouses	
Age (yrs)				
Mean (SD)	45.3	(11.4)	43.1***	(11.5)
Range	21-78		21-75	
Education level (range 1-7)				
Mean (SD)	4.2	(1.7)	3.9**	(1.6)
Employment status				
Work	192	74%	135 ***	52%
No work	67	26%	124	48%
Duration relationship (yrs)				
Mean (SD)	18.9	(12.3)		
Range	0.5-50			
Children				
Yes, children living at home	129	50%	129	50%
Yes, children not living at home	63	24%	64	25%
No	67	26%	66	25%
Type of treatment N, %				
Orchiectomy	68	26.3%		
Orchiectomy & RPLND	20	7.7%		
Orchiectomy & chemotherapy	45	17.4%		
Orchiectomy, chemotherapy & RRRTM	77	29.7%		
Orchiectomy & radiotherapy	49	18.9%		
Time since completion treatment (yrs)				
Mean (SD)	9.3	(6.5)		
Range	0.5-23.8			
Relapse, second cancer N, %				
Tumor relapse	11	4.2%		
Second testicular cancer	8	3.1%		
Second other cancer	7	2.7%		
No	233	90%		

RPLND orchiectomy with retroperitoneal lymph node dissection, RRRTM orchiectomy and chemotherapy and resection of residual tumor mass. SD standard deviation.

** p<0.01; *** p<0.0001

Table 2 Marital and sexual satisfaction of couples during testicular cancer (TC), couples after TC and a reference group of Dutch couples

	Couples during TC n=219		Couples after TC n=40		Reference group n=125	
	M	SD	M	SD	M	SD
Marital satisfaction TCSs/ men	10.0	7.6	11.8	9.0	9.4	8.1
Sexual satisfaction TCSs/men	8.7	7.5	9.3 **	7.7	6.7 ^{oo#}	5.2
Marital satisfaction Spouses/women	12.2	9.9	12.2	11.1	10.9	8.9
Sexual satisfaction Spouses/women	9.4	7.6	9.2	7.9	7.3 ^{oo}	5.4

Higher scores indicate less satisfaction. *M* mean, *SD* standard deviation, *TCSs* testicular cancer survivors.

** $p < 0.01$: Relationship during TC versus relationship after TC

^{oo} $p < 0.01$: Relationship during TC versus reference group

$p = 0.05$: Relationship after TC versus reference group

Couples after TC: TCSs and spouses who started a relationship after TC experienced similar marital satisfaction to that reported by the reference group. TCSs who started a relationship after TC reported less sexual satisfaction than men in the reference group ($t = 1.9$, $p = .05$). Effect size of the difference in sexual satisfaction was 0.38 (95% confidence interval of the difference .15 - .60), indicating that the clinical relevance of the difference was small. The difference in sexual satisfaction between spouses who started a relationship after TC and women in the reference group was not significant ($t = 1.4$, $p = 0.16$) (Table 2).

Are marital and sexual satisfaction of survivors related to those of spouses?

Couples during TC: A paired t -test showed that spouses reported less marital satisfaction than their husbands ($t = -3.2$, $p < 0.01$). No differences were found in sexual satisfaction between TCSs and spouses. Using the cutoff point, 27 (12%) TCSs and 48 (22%) spouses of couples during TC were identified as having a level of marital satisfaction indicating marital problems. A chi-square test showed that significantly more spouses than TCSs scored above the cutoff point ($\chi^2 = 26.3$, $p < 0.0001$). A partial correlational analysis (controlling for age, education level and employment status) showed a significant and positive relationship between marital satisfaction of the TCS and that of his spouse; this correlation was moderate

Table 3 Correlations between marital and sexual satisfaction of testicular cancer survivors (TCSs) and spouses in couples during testicular cancer (TC) and couples after TC

	Marital satisfaction TCS		Sexual satisfaction TCS		Marital satisfaction spouse	
	During TC	After TC	During TC	After TC	During TC	After TC
Sexual satisfaction TCS						
During TC	0.48***					
After TC		0.54***				
Marital satisfaction spouse						
During TC	0.46***		0.41***			
After TC		0.36*		0.51**		
Sexual satisfaction spouse						
During TC	0.36***		0.76***		0.54***	
After TC		0.33*		0.77***		0.60***

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

($r=0.46$). A significant and positive relationship was also found for sexual satisfaction; this correlation was very strong ($r=0.76$) (Table 3).

Couples after TC: A paired t -test showed no differences in marital or sexual satisfaction between TCSs and spouses. Nevertheless, in this group, more TCSs than spouses were identified as having a level of marital satisfaction indicating marital problems: ten (25%) of the TCSs and seven (18%) of the spouses had scores above the cutoff point. This difference was significant ($\chi^2=6.3$, $p < 0.05$). A partial correlation analysis (controlling for age) showed a significant and positive relationship between marital satisfaction of the TCSs and that of their spouses; this correlation was weak ($r=0.36$). For sexual satisfaction a significant and positive relationship was also found; this correlation was very strong ($r=0.77$) (Table 3).

Treatment-related variables in relation to marital and sexual satisfaction.

Couples during TC: Treatment-related variables (time since completion of treatment, type of treatment and experience of a second cancer event) were not significantly related to the marital satisfaction of TCSs. ANCOVA, controlling for age because TCSs who suffered a second cancer event were older than TCSs without ($t=-1.9$, $p < 0.05$), showed that the experi-

ence of a second cancer event was related to sexual functioning ($F=7.4$, $p<0.01$): TCSs who suffered a second cancer event reported less sexual satisfaction than those without. Sexual satisfaction was not related to time since completion of treatment and type of treatment. In spouses of couples during TC, treatment-related variables were not significantly related to marital satisfaction. However, spouses of men with a second cancer event reported less sexual satisfaction than spouses of TCSs without ($t=-2.8$, $p<0.01$). The analyses were not controlled for sociodemographic characteristics because no differences were found between spouses of TCSs who did suffer a second cancer event and spouses of TCSs who did not. *Couples after TC*: Treatment-related variables were not significantly associated with the marital satisfaction of TCSs and spouses or with their sexual satisfaction.

Changes in the existing relationship and the impact on new relationships

Couples during TC: About half of TCSs and spouses (52% and 48% respectively) reported no change in their relationship while 44% of TCSs and 47% of spouses even reported improvement. A very small percentage of TCSs (3.5%) and spouses (5.5%) during TC reported that their relationship had deteriorated. Evaluations of change by TCSs and spouses were significantly and positively correlated ($r=0.41$, $p<0.0001$). Evaluations of change were significantly and positively related to marital satisfaction of TCSs ($r=.28$, $p<0.001$) and spouses ($r=.25$, $p<0.001$), meaning that improvement was related to more marital satisfaction. Positive relationships were also found with sexual satisfaction of TCSs ($r=.25$, $p<0.001$) and spouses ($r=.19$, $p<0.01$), meaning that improvement was related to more sexual satisfaction.

Couples after TC: Testicular cancer had no impact on the relationship in 49% of TCSs and 30% of spouses whereas there was a small impact in 8% of TCSs and 24% of spouses. A large to very large impact was reported by 19% of TCSs and 13% of spouses. TCSs' evaluation of the impact on the relationship was significantly related with that of spouses ($r=0.39$, $p<0.05$) (Table 4). Evaluation of the impact was not significantly related to marital and sexual satisfaction of either TCSs or spouses.

Discussion

The aim of this study was to gain insight into the level of marital and sexual satisfaction in both TCSs and their spouses. Previous research has paid very little attention to sexual satisfaction in spouses of TCSs. Our study population also included a group that has never been investigated before, namely, TCSs and their spouses who started a relationship after diagnosis and treatment (couples after TC). It may be that differences appear in marital and sexual satisfaction between couples who shared the experience of diagnosis and treatment (couples during TC) and couples after TC. Differences were only found in the TCSs themselves. TCSs who had a steady relationship at the time of diagnosis and treatment reported more sexual satisfaction than the TCSs who started a relationship after the completion of treatment. It

Table 4 Evaluations of changes in and influence on the relationship

	TCS		Spouses	
Changes in relationship couples during TC				
Improved a lot	10	4%	11	5%
Improved	83	40%	86	42%
No changes	109	52%	99	48%
Deteriorated	7	3%	10	5%
Deteriorated a lot	1	0.5%	1	0.5%
Missing data	9		12	
Influence on relationship couples after TC				
Very large Influence	1	3%	2	5%
Large Influence	6	16%	3	8%
Moderate Influence	9	24%	12	32%
Small Influence	3	8%	9	24%
No Influence	18	49%	11	30%
Missing data	3		3	

TCS testicular cancer survivor, *couples during TC* couples who had a relationship at time of diagnosis of testicular cancer, *couples after TC* couples who developed a relationship after completion of treatment for testicular cancer

was striking that greater sexual satisfaction applied particularly to TCSs with a longer relationship and an older age, although a younger age was more highly related with better sexual functioning in TCSs (22) and greater sexual satisfaction in the general population (8). This might indicate underlying vulnerability in TCSs as a result of cancer in an area of the body that is related to sexuality and closely associated with it. In a new relationship, insecurity about sexual functioning may arise and be expressed in decreased sexual satisfaction. To gain an impression of the satisfaction of TCSs and their spouses in comparison with couples who have not been confronted by cancer, data were used from a group of 125 couples for comparison purposes. No differences were found in marital satisfaction of couples during and after TC and the comparison group suggesting that the cancer experience does not affect relationship satisfaction. These comparison data were collected twenty years ago, with the possibility that they do not entirely represent today's couples satisfaction. However, other norm data are not available in the Netherlands, and the questionnaire is still used in other current research ((17;28). Besides that, a recent study (12) showed that parents of a child

with cancer reported equal marital satisfaction as the couples of the same comparison group also, which might indicate that data are still valid. In couples during TC, both TCSs and their spouses reported less sexual satisfaction than the men and women in the reference group. Only TCSs in couples after TC reported less sexual satisfaction than their counterparts in the reference group. It appeared that testicular cancer had negative consequences on the sexual relationship for all TCSs and for spouses who experienced the period of diagnosis and treatment also. The clinical relevance of the statistically significant differences found between the study groups and the comparison group in sexual satisfaction appeared to be small to marginal.

Looking at the level of satisfaction within couples, we found a positive relationship for marital and sexual satisfaction in both groups of couples. In other words, when one partner was experiencing greater satisfaction, the other partner was experiencing the same. Although there was a positive relationship in satisfaction for couples during TC, the spouses reported less marital satisfaction than their husbands. In addition, more spouses than survivors had a level of (dis) satisfaction indicating marital problems. This was in agreement with other studies that found differences in the responses of men and women regarding their marriage. Women were generally more dissatisfied with their marriage and if there were differences in judgment about the relationship, then it was usually the woman who was most dissatisfied (24).

Despite the differences in marital satisfaction, there were no differences in sexual satisfaction between TCSs and spouses of couples during TC. Within these couples, satisfaction about the sexual relationship was more strongly related than marital satisfaction. This finding disagrees with earlier research in which a gender gap was prevalent and women experienced less sexual satisfaction than men, although this difference was fairly small (8).

It was striking that in couples after TC, more TCSs than spouses experienced a level of marital (dis) satisfaction indicating marital problems. These TCSs were not only less satisfied about their sexual relationship than men in the reference group and TCSs with a longer relationship, they were also experiencing marital problems more often than their spouses. It may be that the lower level of sexual satisfaction negatively affects their satisfaction with the relationship as a whole. These men may lack the buffer of increased intimacy by having endured the cancer experience together with their spouse.

Time since completion of treatment and type of treatment showed no significant relationships with marital or sexual satisfaction. The group of survivors as a whole seemed to experience less sexual satisfaction as a result of their experience with testicular cancer. However, within this group no effect was found for time since completion of treatment or for the different treatment modalities. These results may imply that psychological factors may be more important in explaining sexual functioning and sexual satisfaction rather than treatment-related biologic-organic factors.

The experience of a second cancer event had an effect on satisfaction, but only on sexual

functioning. In couples during TC, the TCSs with a relapse or a second testicular cancer or another second primary tumor reported less sexual satisfaction, irrespective of their age. The spouses of these men with a second cancer event also reported less sexual satisfaction. Perhaps this relationship was found because their satisfaction about the sexual relationship was strongly related to that of their husband. Physical as well as psychological mechanisms may explain this finding. A second treatment for cancer can deteriorate physical sexual functioning even more, resulting in less sexual satisfaction. Also, the psychological impact of yet another attack on the physical integrity by cancer can cause distrust of one's own body, also resulting in decreased satisfaction.

TCSs and their spouses were asked to report whether confrontation with TC had influenced their marriage. The couples during TC responded to the question of whether their relationship had changed as a result of cancer diagnosis and treatment. Almost half of the couples had not experienced any change in their relationship while more than 40% reported that it had even improved, which is in agreement with earlier research findings (16). Only a small percentage of TCSs (3.5%) and spouses (5.5%) felt that their marriage had deteriorated. Perceived positive changes in the relationship were also related to more marital and sexual satisfaction in this group of couples. This important strengthening influence of cancer on the relationship has been reported previously in other couples in whom one partner had cancer, but also specifically in TCSs and their spouses. In the current study, improvement in the relationship was however not visible in higher marital satisfaction scores than in the reference group. This may have been due to self-reports about satisfaction with the aid of the questionnaire. The difference between "satisfied" and "very satisfied" may not have been quite so clear. Couples after TC were asked to describe whether the fact that the husband had had TC was influencing their relationship. The majority of TCSs (57%) and spouses (54%) reported that the husband's TC had a small or no influence on the relationship.

In summary, confrontation with testicular cancer did not appear to have a negative influence on the marital satisfaction of testicular cancer survivors and spouses who had a steady relationship during diagnosis and treatment. A large proportion reported that the relationship had even improved. Contrastingly, the sexual relationship between survivors and their spouses seemed to deteriorate under the influence of testicular cancer. Owing to the fact that satisfaction in survivors and their partners was almost identical and correlations were strong, any decrease in the satisfaction of the husband will automatically mean a decrease in his spouse's satisfaction. Earlier research has shown that 67% of testicular cancer survivors appeared to have a need for information about sexuality and sexual functioning, even in the longer-term after treatment (13). As testicular cancer also affects the sexual relationship of spouses, they should be included in any discussions or information about the consequences of TC on sexuality.

In couples who developed a relationship after the completion of treatment, confrontation with testicular cancer especially seemed to have negative effects on the survivors themselves.

Their sexual satisfaction was lower than in survivors who had a steady relationship during treatment. They also more often experienced marital problems than their spouses. These men seemed to be a vulnerable group. A study on a larger group of cancer survivors who did not have a partner at the time of treatment might help to provide more insight into possible problems and issues that can affect later partner relationships.

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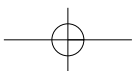
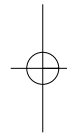
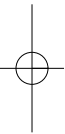
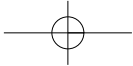
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chapter 4 **expression of negative emotions in testicular cancer survivors and their spouses**

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resubmitted Families, Systems & Health



Introduction

Expression of emotions has several important social functions. It gives other people the opportunity to infer what our intentions and feelings are and to react to our emotions. In fact, many of our emotional expressions have the purpose of affecting and influencing other people, so they can behave to our benefit (1;2). Expressing emotions can be seen as a social interaction having social consequences (3). Not expressing emotions may be useful also when we do not want others to know our feelings. Non-expression can be relevant for example in an attempt not to lose emotional support from others (1;4). It can also be functional when the situation causing the emotions cannot be influenced or controlled or when the emotions experienced are just too strong to handle (1), as may be the case when one is confronted with cancer.

Non-expression of negative emotions such as anxiety, anger and depression, has been related in theory and research to health and disease, also specifically to cancer. Non-expression is most likely a reaction to the stressful experience of cancer, a way of coping with the strong and troubling emotions that often accompany the experience with cancer and its treatment (4-7).

The periods of diagnosis, treatment and completion of treatment have been identified as particularly stressful for cancer patients. The cancer patient is not alone in his experience however. Confrontation with and the diagnosis and treatment of cancer also has a strong impact on the spouse (8-11). Spouses have to deal with strong emotions like anxiety, depression and distress as well. The percentage of spouses reported to have cancer related psychosocial problems at a clinically increased level varies between 18% and 30% (8;12-14). It appears that especially female spouses are at risk of developing psychological problems when confronted with cancer (10;13). Spouses have appeared to engage in 'protective buffering' against cancer patients, as a way of not troubling them by avoiding the discussion of their own fears and concerns (15;16), which might result in decreased emotional expression of especially negative emotions.

Emotional expression has been linked to several mental and somatic health benefits (17-19). Studies on cancer patients showed that emotional expression could improve quality of life and lower depression (20), and buffer negative effects of unsupportive social interactions (21). On the other hand, less expression of emotions has been found to be related to more anxiety and depression after head and neck cancer (22). Emotional expression might also be related to stress response symptoms. When a traumatic experience, like having had cancer, is not resolved properly, stress response symptoms may persist. These symptoms consist of intrusively experienced ideas, images, feelings or bad dreams about the event, or avoidance of unpleasant feelings or memories of the event. Stress response symptoms have been the subject of study in cancer patients and survivors since the early nineties (23). These symptoms can be seen as both an emotional reaction to a traumatic event as well as a mechanism for adaptation, that facilitates recovery through re-experiencing the event. Expressivity

might influence the degree of stress response symptoms by facilitating cognitive processing of the stressful experience (19). Besides this, expression of emotions can be seen as communication and social interaction, and as such may play an important role in marriage. Marital satisfaction can be influenced by the way spouses express their emotions to one another. When the tendency to express negative emotions has changed through the experience with cancer, it may have an impact on the marital relationship.

Until now the vast majority of research on the role of non-expression of emotions has been performed in breast cancer patients (4;24-27), thus not providing insight into the way cancer is related to emotional expression in male patients. Men and women are not found to differ in subjective experience of emotions, but they do seem to differ in the ways they express emotions and in their motives for regulating emotions (28;29). Women are generally more emotionally expressive than men, however men more often express anger and disappointment. It is useful to study emotional expression in male cancer patients as well to address possible differences.

The present study will focus on non-expression of emotions in men who survived testicular cancer and that of their spouses. Testicular cancer mainly strikes young men in the age of 20 to 40 years. It is a highly curable type of cancer, with up to 90% of the patients surviving the disease (30). The present study on testicular cancer survivors (TCSs) and their partners can therefore provide insight into long term adaptation to confrontation with cancer, and into the relationship of non-expression with the functioning of cured cancer patients and their partners. However, some patients are diagnosed with more advanced disease which leads to a more extensive treatment including chemotherapy, which in turn often leads to more disturbing physical and psychological side effects (31;32).

The first aim of the study is to examine if testicular cancer survivors express negative emotions equally often as their spouses and as men not confronted with a cancer experience (controls). The second aim is to investigate the link between emotional expression and objective treatment related variables: time since completion of treatment, type of treatment received and the experience of a second cancer event. The third aim is to examine relationships between emotional expression of testicular cancer survivors and spouses and their own and the other's functioning (stress response symptoms, marital satisfaction and mental health).

Methods

Procedure

All the men treated for testicular cancer between 1977 and 2003 at University Medical Center Groningen in the Netherlands were approached in writing and invited to take part in a questionnaire survey. A total of 702 men received written information explaining the aim of the study, an invitation to participate, an informed consent form, and a prepaid return envelope. An invitation for the spouse to take part was also enclosed. Spouses younger than 18

years and male spouses were excluded to obtain a homogeneous group. A control group of men was formed by requesting the eligible TCSs to invite two similarly aged men from their residential area who had not been confronted with cancer to participate. Testicular cancer survivors, spouses and controls that decided to participate received a self-report questionnaire and a prepaid return envelope. Exclusion criteria were previous psychiatric history, diagnosis within the past six months, and age younger than 18 years. Partners were instructed to complete the questionnaire independently and not to consult each other. The study was approved by the Medical Ethics Committee of the University Medical Center Groningen.

Participants

A total of 354 men (50%) agreed to participate in the study. Analyses showed that non-participating TCSs did not differ from participants in age, marital status, age at time of diagnosis or type of treatment received. Of the 354 survivors, 299 (84%) had an eligible spouse. A total of 259 spouses (87%) agreed to participate. Forty of the TCSs appeared to have started a relationship after treatment completion. These couples were excluded from the present analyses, since the spouses did not experience the period of diagnosis and treatment themselves. Thus, 219 couples, i.e. TC survivors and their spouses, were included in the analyses. No information was available about the spouses who did not wish to participate, because they were invited anonymously via the TCSs. The 354 participating TCSs recruited a comparison group of 258 men who returned a completed questionnaire. To match these men to TCSs on relationship status, singles were excluded from the analyses, resulting in a comparison group of 241 men.

Instruments

TCSs, spouses and controls filled in the same questionnaires. Data were obtained on various demographic aspects: age, education level, employment status, and duration of relationship. Highest level of education completed was measured on a seven-point scale: primary school (1), lower vocational degree (2), middle secondary (3), middle vocational (4), high secondary (5), higher vocational (6), and advanced university (7). Employment status could be indicated as working for wages (full time job & part-time job), or not working for wages (house-keeping, student, unemployed, unable to work, or retired). Information was also obtained from the TCSs on the following disease and treatment related aspects: date of completion of treatment, type of treatment received, and the occurrence of tumor relapse or a second primary malignancy. Type of treatment could comprise: orchiectomy (removal of the affected testicle), orchiectomy with retroperitoneal lymph node dissection (RPLND), orchiectomy and chemotherapy, orchiectomy and chemotherapy and resection of residual retroperitoneal tumor mass (RRRTM) or orchiectomy and radiotherapy.

Expression of negative emotions. The subscale expression of emotions towards others (EEO) of the questionnaire for Emotional Expression and Control was used (33), which is based on the Emotional Control Scale of Watson et al. (34). This questionnaire measures the tendency to control emotional reactions. The subscale EEO consists of 6 items concerning the expression of negative emotions: anxiety, anger and depression. For example 'When I feel afraid or worried, I show others how I feel' or 'When I feel angry or very annoyed, I say what I feel'. Respondents could indicate how they usually react. Each item was measured on a 4-point scale: almost never (1), sometimes (2), often (3) and almost always (4). Scores were summed, therefore the range was from 6-24. Higher scores indicated more emotional expression. Reliability proved to be good, Cronbach's alpha for the EEO scale was .85 for the TCSs, .89 for the spouses and .87 for controls. EEO appeared significantly related to age (33). The older the respondent, the less emotional expression he or she reported; age must therefore be taken into account in statistical analyses.

A self constructed question was added to the EEO. TCSs and spouses were asked: 'Has your expression of emotions changed since the diagnosis of testicular cancer?' Answers could be given on a 5-point scale: 'yes, I express my emotions much less often now' (1), 'yes, I express my emotions a little less often now' (2), 'No, nothing has changed' (3), 'yes, I express my emotions a little more often now' (4), to 'yes, I express my emotions much more often now' (5).

Stress response symptoms were measured with the Impact of Event Scale (35;36). With this questionnaire, information was obtained about the degree to which confrontation with testicular cancer was influencing the current daily life of the respondent. The total score reflects the amount of intrusion (intrusively experienced ideas, images, feelings or bad dreams about the event, (7 items), and avoidance of unpleasant feelings or memories of the event (8 items) the respondent experiences. A higher score reflects more stress response symptoms. The Dutch version of the IES indicates a total score of more than 26 as severe stress response symptoms, for which psychological help is recommended. The IES is a valid instrument for measuring cancer related stress response symptoms (37;38). Internal consistency in this study was good for TCSs (alpha = .85) and spouses (alpha = .92).

Marital satisfaction The subscale marital satisfaction of the Maudsley Marital Questionnaire (MMQ) was used to measure marital satisfaction (39). The MMQ-M defines marital satisfaction as the subjective evaluation of the emotional connection. Each of the 10 items was measured on a 9-point scale (0-8). Respondents were asked to indicate which point on the scale best described their situation over the past two weeks. Items were summed, with a higher score indicating more dissatisfaction. Previous research has shown that the MMQ is a reliable and valid instrument for the measurement of marital quality (39-42). Reliability of

the MMQ in the present study was good. Cronbach's alpha for TCSs was 0.82 and for spouses 0.89.

Mental health The five-item subscale mental health of the RAND-36 was used (43;44). The RAND-36 is an internationally used valid and reliable generic self-report questionnaire to assess general Quality of Life (QoL) (45). Example of items include: How much of the time during the past 4 weeks... 'Have you felt calm and peaceful?', 'Have you felt downhearted and blue?', or 'Have you been a happy person?'. After recoding and transformation, scores could range from 0 to 100. Higher scores indicate better mental health. Internal consistency of the subscale for spouses ($\alpha = 0.75$) and TCSs ($\alpha = 0.81$) was good.

Statistical analyses

The database of TCSs and spouses consisted of matched pairs, making pairwise comparisons possible. A separate database was constructed for TCSs and controls. ANCOVAs were performed to compare EEO of TCSs with that of controls, controlling for demographic characteristics that differed significantly between them. As data obtained from partners were not independent, paired *t*-tests were performed to analyse differences between TCSs and spouses in emotional expression. To assess the magnitude of differences found effect sizes were calculated using Cohen's *d* with the formula: mean group 1 minus mean group 2 / pooled standard deviation of groups 1 and 2 (46). Middel et al. showed that effect sizes also reflect clinical relevance. Differences resulting in large effect sizes imply that a (psychosocial) intervention is warranted. An $ES < 0.20$ indicates 'no relevance', $ES \geq 0.20 < 0.50$ as 'low relevance', $ES \geq 0.50 < 0.80$ as 'moderate relevance' and $ES \geq 0.80$ as 'considerable relevance' (47).

Partial correlation analyses (controlling for age) were conducted to examine the relationship between EEO and time since completion of treatment, for both TCSs and spouses. Dichotomous variables were created for stress response symptoms (below (0) and above (1) cut-off point for clinically elevated levels), type of treatment received and for occurrence of a second cancer event. Independent *t*-tests were computed to investigate differences in EEO between groups based on type of treatment (0 = 'surgical treatment' (orchiectomy and orchiectomy plus RPLND) and 1 = 'combined treatment' (orchiectomy plus chemotherapy, or plus chemotherapy and RRRTM or plus radiotherapy)), a second cancer event (0 = no relapse, second diagnosis of TC or a second other cancer diagnosis), and clinically elevated stress response symptoms. Partial correlations (controlling for age) were computed to examine relationships between EEO and stress response symptoms, marital satisfaction, and mental health.

Results

Descriptives

TCSs were significantly older ($t=9.9$, $p<.001$), had completed an education of higher level ($t=2.8$, $p<.01$) and more of them had a job ($\chi^2=20.6$, $p<.001$) than spouses. TCSs had completed a lower education level ($t=-2.6$, $p<.01$) and had a relationship of longer duration ($t=2.8$, $p<.01$) than controls. Spouses had completed a lower education level ($t=-4.9$, $p<.001$) and had a job less often ($\chi^2=41.7$, $p<.001$) than controls (Table 1).

Table 1 Demographics and illness related variables

	TCSs n=219		Spouses n=219		Controls n=241	
Age (yrs)						
Mean (SD)	46.2	(11.6)	44.2 ***	(11.6)	44.3	(10.6)
Range	21-78		21-75		22-73	
Education level (range 1-7)						
Mean (SD)	4.1	(1.7)	3.8 **	(1.5)	4.6 ^{oo+++}	(1.7)
Employment status						
Work	163	74%	112 ***	51%	192 ***	80%
No work	56	26%	107	49%	49	20%
Duration relationship (yrs)						
Mean (SD)	20.8	(12.1)			17.7 ^{oo}	(11.2)
Range	0.5-50				0.5-44.5	
Type of treatment N, %						
Surgery only	74	34%				
Combined treatment*	145	66%				
Time since treatment completion (yrs)						
Mean (SD)	8.8	(6.5)				
Range	0.5-24					
Second cancer event N, %						
Tumour relapse	7	3%				
Second testicular cancer	8	4%				
Second other cancer	7	3%				
No	197	90%				

TCSs vs spouses ** $p<.01$; *** $p<.001$; TCSs vs controls^{oo} $p<.01$; Spouses vs controls⁺⁺⁺ $p<.001$

* surgery plus chemotherapy, or plus chemotherapy and resection of residual retroperitoneal tumormass, or plus radiotherapy.

Comparison of expressing negative emotions between TCSs and controls

ANCOVA (controlling for education level and relationship duration) showed that TCSs reported less EEO than controls ($F=76.4$, $p<.001$). Effect size of this difference was $-.81$ (95% confidence interval of the difference -1.00 to -0.62), indicating a very large and clinically relevant difference (Table 2).

Differences in expressing negative emotions, marital satisfaction and mental health

Paired t -test showed that TCSs reported less EEO than their spouses ($t=-4.9$, $p<.001$). Effect size of this difference was $-.46$ (95% confidence interval of the difference $-.65$ to -0.27), indicating a small difference. Patients reported more marital satisfaction than spouses ($t=2.6$, $p<.01$) and controls ($F=5.0$, $p<.05$) (Table 2).

Table 2 Descriptives of emotional expression, stress response symptoms, marital satisfaction and mental health

	TCSs		Spouses		Controls	
	mean	(sd)	mean	(sd)	mean	(sd)
Emotional expression	13.1	(3.7)	14.9 ***	(4.1)	16.2 ^{ooo}	(3.9)
Total stress response symptoms	8.3	(10.8)	10.7	(13.8)		
Clinically elevated stress response symptoms (n, %)	18	8%	29	13%		
Marital satisfaction	10.0	(7.6)	12.2**	(9.9)	12.0 ^o	(9.2)
Mental health	78.7	(14.9)	76.3	(15.1)	79.4	(12.7)

TCSs vs spouses: ** $p<.01$ *** $p<.001$

TCSs vs controls: ^o $p<.01$ ^{ooo} $p<.001$

Survivor's and spouses' evaluation of changes in expression of emotions since diagnosis

As a response to the question 'Has your expression of emotions changed since the diagnosis of testicular cancer?' 43% of TCSs and 56% of spouses reported no change. Almost half of the TCSs (48%) and one third of the spouses (31%) reported they expressed a little or a lot more emotions since diagnosis. A small group of TCSs (10%) and spouses (13%) reported they expressed their emotions much less or a little less. TCSs and spouses differed in their reported change in emotional expression ($\text{Chi}^2 = 36.9$, $p<.01$). TCSs more often reported an increase in emotional expression than spouses, and spouses more often reported no change (Table 3).

Table 3 Perception of change in expression of emotions

	TCSs		Spouses	
	N	%	N	%
Much less often	6	3	10	5
A little less often	14	7	18	8
No change	91	43	118	56
A little more often	71	34	48	23
A lot more often	29	14	18	8
Missing	8		7	

Relationship between emotional expression and illness and treatment related variables

Partial correlation analysis (controlling for age) showed one significant but weak negative relationship between time since completion of treatment and EEO for spouses only ($r=-.19$, $p<.01$). The longer treatment had been completed, the less spouses expressed negative emotions. Independent *t*-test showed no differences in EEO in TCSs and spouses according to type of treatment. ANCOVA (controlled for age) showed no effect of the experience of a second cancer event on his or her expression of emotions.

Relationships between emotional expression, stress response symptoms, marital satisfaction and mental health

Means for stress response symptoms, marital satisfaction and mental health for survivors and spouses are shown in Table 2. Only one significant but weak positive relationship between emotional expression and functioning was found: emotional expression of spouses was related to her own total stress response symptoms ($r=.14$, $p<.05$), meaning that the more she expressed her negative emotions the more stress response symptoms she experienced. Besides that, spouses that reported elevated stress response symptoms reported to express negative emotions more often ($t=-2.4$, $p<.05$). Stress response symptoms, marital satisfaction and mental health of survivors were not related to emotional expression of spouses. Stress response symptoms, marital satisfaction and mental health of spouses were not related to emotional expression of survivors. For controls a significant relationship between emotional expression and marital satisfaction was found ($r=.21$, $p<.001$), meaning that the more negative emotions controls expressed, the less marital satisfaction they experienced and vice versa. No relationship between expression and mental health was found for controls. No regression analyses were performed since no other significant univariate relationships were found between emotional expression and functioning in patients and spouses.

Discussion

The focus of this study was on the expression of negative emotions such as anxiety, anger and depression in a large group of long-term testicular cancer survivors and their spouses. It appeared that male survivors expressed anxiety, anger and depression less often than did men who did not experience cancer. This difference was found to be highly clinically relevant, meaning that an intervention might be warranted. This finding suggests that the experience with cancer seems to be associated with a decrease in the expression of negative emotions.

Spouses reported they expressed negative emotions more often than survivors did, which is in line with previous literature. Women have been found to be more expressive than men of emotions that can be regarded as 'powerless' such as fear and sadness (28), emotions also addressed in the current questionnaire. A comparison between a group of male and female cancer patients a mean of five years after diagnosis, also showed a trend for higher expressivity in the female group (29).

What was striking in light of these findings, was the subjective judgement of half of the survivors (48%) that they expressed emotions more often since the diagnosis. This was an answer to a more generic question, without emphasis on either negative or positive emotions. It may be that survivors do express positive emotions like happiness, love and joy more often, but have changed the frequency of expressing negative emotions. The subjective judgement of spouses of changes in their own emotional expression is somewhat different from the survivors. A smaller percentage (31%) of the spouses as compared to the survivors indicated that they express emotions a little or a lot more since their husbands' illness, while a greater percentage (56%) as compared to the survivors reported no change in expression of emotions.

Stress response symptoms reflect how much distress is still experienced after a traumatic event, and is often studied in cancer patients and survivors. Emotional expression appeared to be not related to the survivor's stress response levels. In contrast, emotional expression of spouses was weakly related to her own stress response symptoms: the more spouses expressed negative emotions, the more stress response symptoms they reported. Besides, spouses who experienced clinically elevated levels also reported more expression of negative emotions. An explanation for these different findings in survivors and spouses is not quite clear and contradictory to other research, in which emotional disclosure has been found related to reduced avoidance (a component of stress response) in cancer patients (21).

Emotional expression of survivors and that of spouses was found to be not related to marital satisfaction nor to the level of stress response of the partner. The suggestion that emotional expression might be related to communication within couples and therefore affect marital satisfaction after cancer can not be supported in this study. A relationship however was found in controls: more negative expression was related to less marital satisfaction. This may be a reflection of a less satisfying relationship as well. It may be that marital satisfaction of

survivors and spouses is quite stable, as all couples were in a relationship since before diagnosis. Results on the relationship between expression and marital satisfaction for all couples confronted with testicular cancer, including those who get divorced or who experience marital problems, might be different and deserve to be investigated. Again, no relationships between expression on the one hand and mental health on the other were found for patients and spouses. This is in contrast with an earlier study on testicular cancer survivors that showed that survivors who tended to conceal their emotions reported more sexual impairment accompanied with more distress than survivors who tended to express their emotions (48). However, this tendency to conceal was measured with a subscale of a questionnaire focussing on masculinity, which is not comparable to the questionnaire on emotional expression we used. In addition, the relationship with concealment is probably a reflection of feeling uncomfortable talking about sexual problems specifically.

Although the experience with testicular cancer seemed to have affected emotional expression in survivors, emotional expression appeared not linked to type of treatment or a second confrontation with cancer. And, more surprisingly, expression of survivors was also not related to time since completion of treatment, even though it varied between 1 and 24 years. It may be that the cancer experience in itself affects functioning rather than illness and treatment related aspects. Subjective perceptions, like ideas about long-term consequences of the disease and fear of recurrence, have been found to be more important contributors to cancer-related distress than objective variables (49;50). Results did show that the longer treatment had been completed, the less spouses express negative emotions, irrespective of their age.

In sum, expression appeared decreased in testicular cancer survivors, but this had no relationship with either his own psychosocial functioning nor with that of his spouse, suggesting that the decrease had no negative consequences. An alternative explanation for the decrease in expression of negative emotions might lie in a change in life regard. It may be that survivors experience positive consequences following the cancer experience, and may choose to focus on the good things in life and therefore express negative emotions less. Indeed, some studies have shown positive consequences also of the experience with cancer, such as appreciation of self, life in general and the relationship with the partner (51), and also specifically for testicular cancer survivors an improvement in many areas of their lives such as outlook on life, self respect and satisfaction with life (52). Also husbands of breast cancer survivors have reported posttraumatic growth: positive life changes after the trauma, showing that couples can also share the possible gain of their experience together (53). Possible positive changes might explain the decrease in tendency to express negative emotions in testicular cancer survivors, apart from the explanation that this is a coping strategy in dealing with remaining anxiety and depression in an attempt to master these feelings. A greater focus on the good things in life does not leave much room for expressing anger, anxiety or depression. The expression of positive emotions and posttraumatic growth were not the focus of the present

study, but results indicate that this should be incorporated in future studies on adaptation after testicular cancer.

This study has some limitations. First, the comparison group of men was recruited from the network of the testicular cancer survivors who were instructed to approach men similar in age and socioeconomic status. It appeared that the recruited comparison group was more highly educated suggesting that survivors recruited friends and neighbours who were more successful in some ways, this was found before in other studies (54). However, controls reported comparable mental health as survivors, suggesting no big differences in psychological functioning exist between them. Second, the current study has a cross-sectional design, which does not allow for causal conclusions about the relationship between the experience of testicular cancer and the level of emotional expression. Third, respondents were long-term survivors, making the cancer episode a remote event for most men. It might very well be that changes in expression are related to functioning when treatment was completed more recently. Besides, no information was available on the functioning of couples who declined to participate. These might well be the couples who are low in emotional expression and disclosure. They also may have been those who were functioning best or worst, thus biasing the results in either direction.

Conclusions

This study shows that testicular cancer survivors significantly express negative emotions less often than men not confronted with cancer. Emotional expression of survivors was not related to his stress response symptoms, marital satisfaction or mental health nor to that of his spouse. Perhaps the decrease in expression of negative emotions is a sign for a more positive outlook on life in this group.

Practice implications

Earlier studies on emotional expression have addressed the beneficial effects of expression and disclosure on dealing with stressful events, like diagnosis of and treatment for cancer (1;18;21;55). However, in this group of long term male cancer survivors, emotional expression was unrelated to psychosocial functioning. The lowered emotional expression in this group might have no consequences on functioning, suggesting there is no need for any intervention to facilitate expression.

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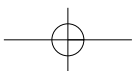
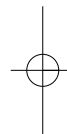
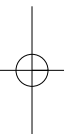
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**chapter 5 testicular cancer:
a longitudinal pilot study on
stress response symptoms and
quality of life in couples before
and after chemotherapy**

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Introduction

Testicular cancer is a rare disease, although it is the most common tumour in men aged 20-35 years. About 500 new cases are diagnosed each year in the Netherlands (1). Testicular cancer is distinguished into seminomas and non-seminomas, and each type accounts for about half of the total. Half of the men with a non-seminoma are diagnosed with disseminated disease, that is treated with chemotherapy (2). Since the introduction of cisplatin-based chemotherapy in the late nineteen seventies, up to 80% of the patients with disseminated disease can be cured (3-5).

Chemotherapy for testicular cancer has several acute physical side effects like nausea, fatigue, and neuropathy (6). On a psychological level, patients receiving chemotherapy have been found to report anxiety, depression and distress (7-10). The partners of testicular cancer patients receiving chemotherapy may encounter adverse sequelae, as well. Partners have to struggle with the fear of potentially losing their significant other. Partners are the primary source of information for family members and friends, while their husbands are admitted to the hospital. In addition to this social task, partners often take on the caregiver role between chemotherapy cycles. Care giving for cancer patients has been found to negatively impact on caregiver's physical and mental health (11-13).

The impact of testicular cancer on younger couples might differ from the impact on couples who face cancer at an older age. The young couples confronted with testicular cancer might not have been together for a substantial period of time. This can make the relationship more vulnerable to the stressors induced by major life events. Earlier studies have showed that relationships of shorter duration are more sensitive to disruption after a testicular cancer diagnosis (14;15), although another study did not find such a connection (16). Also, couples are confronted with possible treatment-related infertility and sexual difficulties at a time in life where partners are often focused on starting a family. Couples may face several individual and dyadic stressors after the diagnosis of testicular cancer, leading to the experience of distress and lowered quality of life. This is particularly true when chemotherapy is part of the treatment protocol, as it is a more demanding treatment modality than surgery alone, in the case of testicular cancer.

Several prospective studies focused on dyadic adjustment and functioning from cancer diagnosis in a variety of sites, up to one and a half year later (17-20). Although both patients and partners were reported to suffer from distress, levels of distress did not necessarily correspond within couples. Different patterns of distress and adjustment were found to be associated with gender and health status. Some studies reported that female partners were most vulnerable since they reported higher levels of distress than female and male patients and male partners (20-22).

One pilot study examined the course of distress and quality of life in testicular cancer patients before, during and after chemotherapy (complete data on 10 patients) (23). Patients reported highest levels of distress shortly before the start of chemotherapy. Distress

and anxiety decreased over time. We chose to expand the findings of this study by including partners in our study in order to investigate the adjustment of couples facing testicular cancer during the first year after diagnosis. Patterns of stress response symptoms and quality of life of patients and partners were examined at three time points during the first year. Goals of the present study were: (1) to explore differences and relationships between patients' and partners' stress response symptoms and quality of life (QoL); (2) to examine change over time in stress response symptoms and QoL in patients and partners; (3) to relate earlier levels of stress response symptoms and QoL in patients and partners to later levels; and (4) to examine differences in QoL of patients and partners with that of a reference group of men and women.

Methods

Procedure and participants

All patients diagnosed with a disseminated nonseminomatous testicular tumour, who consecutively visited the University Medical Center Groningen (UMCG) in The Netherlands for treatment between April 2001 and March 2004, and who were married or cohabiting were approached for this study. Exclusion criteria were a psychiatric history, age younger than 18 years at study entry, insufficient command of the Dutch language, and previous treatment for cancer. The study was introduced to the patients and their partners after orchiectomy (removal of the affected testicle) was performed. Couples received a questionnaire at the following three time points: after orchiectomy but before the start of chemotherapy (T1), immediately after chemotherapy completion, which is approximately three months after T1 (T2), and one year after T1 (T3). The patients received four cycles of cisplatin, etoposide and bleomycin, with a three-week interval between each cycle. Couples received a letter with information about the objectives of the study, an informed consent form, the questionnaires, and a prepaid return envelope. Thirty eligible couples were approached to participate in the study, of whom 21 participated (70%). Two couples did not complete all three measurement times, therefore 19 couples provided complete data. The study was approved by the Medical Ethics Committee of the University Medical Center Groningen.

Measurements

Sociodemographics: Data on the following sociodemographic variables were collected at T1: age, educational level, employment status, and duration of the relationship. Highest educational level completed was measured on a seven-point scale: primary school [1], and lower vocational [2], lower secondary [3], middle secondary [4], high secondary [5], higher vocational degrees [6], and university [7]. Employment status could be indicated as employed for wages, housekeeping, student, unemployed, unable to work, or retired.

Stress response symptoms were measured with the Impact of Event Scale (24;25). This scale (15 items) makes an inventory of the extent to which a subject is currently occupied with an

event by measuring intrusion (intrusively experienced ideas, images, feelings or bad dreams about the event, 7 items) and avoidance of unpleasant feelings or memories of the event (8 items). The IES is often used in studies on cancer patients (26). With this questionnaire, information was obtained about the degree to which confrontation with testicular cancer was influencing the current daily life of the respondent. Higher scores indicate more stress response symptoms. A total score of more than 26 indicates severe stress response symptoms, for which psychological help is recommended. Reliability of this scale was good for patients (Cronbach's alpha for the different measurement times ranged from 0.82 to 0.89) and for partners (Cronbach's alpha for the different measurement times ranged from 0.78 to 0.93).

Quality of life was measured with three subscales of the RAND-36 (27): physical functioning (10 items), social functioning (2 items) and mental health (5 items). To avoid statistical problems due to multiple comparisons, we chose these three subscales as a representation of overall QoL. The RAND-36 measures generic QoL. After recoding and transformation, scores on the subscales could range from 0 to 100. Higher scores indicate a better QoL. Reliability of these scales was good to very good for patients (Cronbach's alpha for the different measurement times ranged from 0.67 to 0.90) and for partners (Cronbach's alpha for the different measurement times ranged from 0.75 to 0.92). The Dutch manual for the RAND-36 provides reference scores. These comprised the mean scores of a group of 691 non-selected men and 372 non-selected women from a random representative sample of persons aged 18 years and older from the population register of a municipality in the north of The Netherlands (no. of inhabitants = 108,000). The mean age of the persons in the total random sample was 44.1 years (range 18-89 years) (27).

Statistical analyses

Paired *t*-tests and Chi-square test were performed to examine differences in sociodemographics between patients and partners. Wilcoxon signed rank test (because of small sample size) and correlations were computed to examine differences and relationships in stress response symptoms and QoL between patients and partners. Repeated measures analysis of variance (ANOVA) was used to examine change over time in functioning. Pearson's product moment correlations were calculated to examine relationships between the functioning of patient and that of the partner and between measurement times. Strong correlation coefficients (>0.50) indicate consistency between measurement times and stable responses between earlier and later levels of functioning. Independent *t*-tests were performed to compare QoL of patients and partners with those of a reference group of men and women.

Results

Sociodemographic and treatment related variables

Sociodemographic and treatment related variables are reported in Table 1. Patients were older than partners ($t=-3.1$, $p<0.01$). Eighteen patients were employed for wages and one was a student, whereas eleven partners were employed for wages, four were home-keepers and the remaining four partners were students (Chi-square = 19.0, $p=0.04$). After chemotherapy was completed (at T2), all patients were restaged. Patients without biochemical or radiological abnormalities were considered to have reached complete remission ($n=8$). In case of proven residual disease, a resection of residual retroperitoneal tumour mass (RRRTM) was performed. Eleven patients underwent this surgery and were considered to be in complete remission afterwards. None of the 19 patients experienced a relapse during follow up (up to T3).

Table 1 Descriptives sociodemographic and treatment related variables

	Patient		Partner	
	Mean	SD	Mean	SD
Age (years) **	31.6	6.6	28.9	7.6
Range	19.9 – 43.5		19.8 – 44.7	
Duration relationship (years)	5.7	6.3		
Range	1 - 22			
Education level	3.6	1.4	4.0	1.6
	N	%	N	%
Employment status *				
Employed for wages	18	95%	11	58%
Student	1	5%	4	21%
Housewife			4	21%
RRRTM +				
Yes	11	58%		
No	8	42%		

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

+ RRRTM resection of residual retroperitoneal tumour mass

Relationships between patients' stress response symptoms and QoL and those of partners

At T1, stress response symptoms of patients were moderately strongly and negatively related to those of partners ($r = -0.48$, $p < .05$). At T2, social functioning of patients was moderately strongly and positively related to that of partners ($r = 0.53$, $p < .05$). At the three measurement times all other correlations between patients' stress response symptoms and QoL and those of partners were low to moderate, ranging from $r = 0.04$ to $r = 0.34$, and not statistically significant. At T1, in two couples, both patient and partner experienced stress response symptoms above the cut-off point. At T2 and T3 there were no couples in which both patient and partner experienced stress response symptoms above the cut-off point. Wilcoxon tests showed only one significant difference between patients' and partners' functioning. At T2, patients reported a lower level of physical functioning than did partners ($Z = -2.6$, $p < 0.01$).

The course of stress response symptoms and QoL over time in patients and partners

Repeated measures ANOVA showed that the stress response symptoms of patients fluctuated according to a quadratic trend: the highest level was reported at T1, and after a decrease at T2, the level went up again somewhat at T3. Earlier levels of stress response symptoms in patients were highly positively related to later levels (Table 2). At T1, 5 of the patients (26%) reported stress response levels above the cut off point; at T2, 2 patients (11%); and at T3, 3 patients (16%). Two patients reported clinically elevated levels of stress response levels at all measurement times. For partners the level of stress response symptoms declined, via a linear trend. Partners' reports of stress response levels were moderately strongly related between T1 and T2, strongly between T2 and T3, and the relationship between T1 and T3 was weak (Table 2). At T1, 10 of the partners (53%) reported stress response levels above the cut off point, at T2, 6 (32%) and at T3, 2 (10.5%). One partner reported clinically elevated levels of stress response levels at all measurement times.

Lower physical functioning was reported by patients at T2 as compared to T1, but physical functioning returned to baseline level at T3. Earlier levels of physical functioning in patients were not significantly related to later levels, and correlations were low. A decline in social functioning of patients was also found at T2 compared to T1, but higher social functioning than at baseline was found at T3. Social functioning of patients at T1 was positively and strongly related to functioning at T2, but the relationships between T2 - T3 and T1 - T3 were low to moderate. Mental health of patients improved over time. Mental health at T1 was positively and strongly related to levels at T2, and weakly to levels at T3. The relationship between mental health at T2 and T3 was moderately strong.

For partners, no significant time effects were found for physical functioning and mental health. Earlier levels of physical functioning and mental health of partners were highly and positively related to later levels. Social functioning of partners improved over the year, and was highly positively related between T1 and T2, and between T1 and T3. The relationship between T2 and T3 was moderately strong. (Table 2).

Table 2 Stress response symptoms and Quality of Life of patients and partners

	T1	T2	T3	Reference group	Repeated measures ANOVA	T1 - T2	T2 - T3	T1 - T3
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	F	r	r	r
					p	p	p	p
Stress response symptoms								
Patient	18.1 (13.0)	10.2 (10.7)	12.3 (9.9)		7.9	.012	0.65	.002
Partner	25.8 (9.3)	15.2 (12.6)	12.1 (12.4)		17.7	.001	0.41	<i>ns</i>
							0.71	.001
							0.64	.003
								0.16
								<i>ns</i>
Physical functioning								
Patient	93.4 (10.8)	70.5 (23.4)	92.6 (13.3)	84.5 (22.3) ^{oo##+}	21.4	.0001	0.28	<i>ns</i>
Partner	90.2 (19.0)	90.8 (19.0)	89.7 (19.9)	80.7 (23.6) ^{o#}	0.19	<i>ns</i>	0.79	.0001
							0.38	<i>ns</i>
							0.80	.0001
								0.20
								<i>ns</i>
Social functioning								
Patient	77.6 (19.7)	71.1 (22.8)	90.8 (13.1)	88.4 (19.6) ^{o##}	9.0	.008	0.61	.009
Partner	72.1 (20.2)	77.6 (20.7) ^{**}	84.5 (16.5)	86.1 (20.9) ^{oo}	12.9	.002	0.60	.007
							0.37	<i>ns</i>
							0.19	<i>ns</i>
							0.37	<i>ns</i>
								0.68
								.001
Mental health								
Patient	68.2 (22.3)	77.5 (11.9)	81.9 (13.4)	79.4 (17.3) ^o	6.7	.019	0.55	.017
Partner	69.1 (13.6)	71.2 (15.6)	74.3 (15.1)	75.5 (18.9)	2.6	<i>ns</i>	0.72	.0001
							0.33	<i>ns</i>
							0.64	.004
								0.52
								.023

Wilcoxon test patients and spouses ** p < 0.01
 independent t-test T1 and reference group ° p < 0.05, °° p < 0.01
 independent t-test T2 and reference group # p < 0.05, ## p < 0.01
 independent t-test T3 and reference group + p < 0.05

QoL of patients and partners compared to that of a reference group of men and women At T1, patients ($t=-3.4$, $p<0.01$) and partners ($t=-2.1$, $p<0.05$) reported better physical functioning than the reference groups. Patients ($t=2.3$, $p<0.05$) and partners ($t=2.9$, $p<0.01$) reported worse social functioning than the reference groups at T1, and patients ($t=2.2$, $p<0.05$) reported worse mental health at T1. At T2, patients reported worse physical functioning than the reference group of men ($t= 2.6$, $p<0.02$) but partners reported better physical functioning than the reference group of women ($t=-2.2$, $p<0.05$). Patients also reported worse social functioning than the reference men at T2 ($t=3.3$, $p<0.01$). No differences were found between the patients' and partners' mental health and the norm groups at T2. Only one significant difference was found at T3: patients reported better physical functioning than men in the reference group ($t = -2.6$, $p <0.02$) (Table 2).

Discussion

The present study was the first to prospectively and longitudinally examine psychosocial functioning in testicular cancer patients and their partners. We focused on stress response symptoms and quality of life (physical functioning, social functioning and mental health) after orchiectomy but before the start of chemotherapy, immediately after completion of chemotherapy, and nine months later (one year follow-up).

Stress response symptoms in couples were most salient before the start of chemotherapy. Twenty-six percent of patients reported clinically elevated stress response symptoms at this time, a number comparable to the 30% of patients with clinically elevated distress found in a recent study on testicular cancer patients (28). A review of stress response syndromes in adult cancer populations showed that the incidence of clinically elevated stress response symptoms ranged from 3% to 4% in patients recently diagnosed with early stage cancer (26). The majority of these studies used the same questionnaire for measuring stress response symptoms as we did. The same review identified younger age, greater proximity to diagnosis, more advanced disease and greater treatment intensity as risk factors for a higher level of stress response symptoms. The much higher percentage found in our study at the first measurement time may be explained by the prevalence of these four risk factors in our patient group. Not only did patients appear distressed, but also almost twice as many of the partners as compared to patients reported clinically elevated levels of stress response symptoms. Female sex has been found to correlate with greater stress response symptomatology in cancer populations (26). Of course, these spouses are not patients themselves, but obviously they face cancer related fears and worries as well. Our results affirm earlier findings that female spouses of cancer patients are vulnerable to distress, and often report higher levels of distress as compared to their male counterparts (20;21;29-31).

Stress response symptoms in couples decreased after completion of chemotherapy. One year after diagnosis, stress response levels in patients rose slightly, but they continued to decrease in partners. These patterns suggest that the period before chemotherapy commences is most

stressful, and that recovery seems to occur within a year. At the time of the first measurement the responses of the couples seem to be coloured by the fact that they had recently learned the diagnosis, and the outcome of treatment remained uncertain. Concerns of couples about side effects of chemotherapy such as nausea, the possibility of immunodeficiency and hair loss may contribute to distress. Partners also have caregiving tasks that can exacerbate their distress (22). All couples in this study received positive news about the results of treatment, and one year after diagnosis none of the patients had experienced a relapse of disease. Couples seemed to have recovered from this major life event over the year, possibly as a consequence of the success of treatment reducing insecurity about outcome.

An interesting finding was that before commencement of chemotherapy, the level of stress response symptoms of patient and partner was inversely related. When one spouse was reporting more stress response symptoms, the other reported less. This might be a psychological mechanism through which spouses want to protect one another from their own distress, a finding reported before in studies on couples facing cancer (29). Another possible interpretation might be that patients who expressed very low levels of distress were using denial, avoidance, or other repressive psychological mechanisms while their partners carried the psychological burden of stress. A patient who expresses high distress may also allow his spouse to assume a stronger supportive role, and thus reduce her expression of stress.

In line with the medical trajectory, physical functioning of patients was worst after completion of chemotherapy. As a consequence of chemotherapy, many patients still experience adverse side effects, including fatigue and a sense of physical exhaustion. Surprisingly, physical functioning of patients was better than that of the reference group before start of chemotherapy and one year later. The first measurement occurred shortly after removal of the affected testicle, and patients may have experienced physical relief after the initiation of treatment. It may also be that age contributed to the difference found between the patient group and the reference group. Younger age is associated with better physical functioning (27), and the mean age of the patients in this study was somewhat more than ten years lower than that of the reference group. There may have been other differences from the reference group as well, such as physical activity, SES, etcetera. Partners' physical functioning did not change over the year but they also experienced better physical functioning than the reference group before and after chemotherapy. In an earlier study we found that partners of testicular cancer survivors reported better physical functioning than a reference group of women even years after diagnosis (32). Partners of testicular cancer patients may have changed the evaluation of their own health in a positive way after witnessing the diagnosis and treatment of a life threatening illness.

In patients, social functioning was worst immediately after completion of chemotherapy, and in spouses before start of chemotherapy. Before start of chemotherapy, both partners reported worse social functioning as compared to the reference groups. Before chemotherapy starts, couples are probably overwhelmed by the implications of a cancer diagnosis, and

focusing on the treatment to come rather than on being socially active as usual. As a consequence of chemotherapy, patients may still suffer from negative side effects like fatigue and impaired physical functioning, which in turn may affect their social functioning. 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. 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. This finding is in line with studies on testicular cancer survivors that show little or no change in social contacts and work activities (6;33).

Mental health of patients improved over the year. It was poorer than that of men in the reference group only before start of chemotherapy. Mental health of partners was comparable throughout the year and to that of a reference group of women, despite the high level of stress response symptoms they reported before start of chemotherapy. Stress response symptoms apparently are a different expression of mental functioning, and may be encapsulated or separated out.

It appeared that functioning in couples facing testicular cancer was not similar in patient and partners. Testicular cancer patients showed u-shaped trajectories of stress response symptoms, physical and social functioning, a pattern seemingly following the medical trajectory they had undergone. Mental health of patients improved over the year. Spouses reported a decline in stress response symptoms and an improvement in social functioning, but no change in physical functioning or mental health over the year. Differences between patients and partners were also noticeable in stability of functioning. In patients, earlier levels of stress response symptoms were strongly predictive of later levels while less individual stability was found with regard to physical and social functioning and to mental health. Partners reported less individual stability in stress response symptoms over time, although individual stability was found between T2 and T3. However, partners were individually highly consistent in their reports of physical functioning and somewhat less strong in mental health and social functioning. In addition, correlations between the functioning of patients and partners were moderate to very low. We also found that at the second and third measurement time, there were no couples in which both the patient and the partner reported clinically elevated levels of stress response symptoms. This finding confirms the lack of correspondence in functioning between patient and partner.

These findings support recent studies that found different adjustment patterns for patients and partners, and a lack of correspondence in functioning (19;20). Research is needed to examine if these different reaction patterns to a cancer diagnosis affect the marital relationship.

This study has some limitations. First, the possibility of including couples was limited because testicular cancer has a low incidence. Besides, no information was available on the functioning of couples who declined to participate. They may have been those who were functioning

best or worst, thus biasing the results in either direction. Because of the limited sample size, variables that measure relationship aspects were not included in this study. In a previous retrospective study on testicular cancer, factors identified as important for couple adjustment like good communication, spousal support, and marital satisfaction all appeared to facilitate better functioning (34). These moderating factors in adjustment of both patient and spouse deserve to be studied prospectively in the future.

In summary, this study was a prospective exploration of functioning in couples facing testicular cancer during the first year after the diagnosis. Patients confronted with disseminated testicular cancer and their partners reacted differently to this stressor. Clinically elevated stress response levels were present in one third of patients and half of the partners before start of chemotherapy. Patients reported worst mental health before start of chemotherapy, and worst physical and social functioning immediately after completion of chemotherapy. Partners reported an improvement in social functioning, and no change in physical functioning and mental health over the year. Quality of life of patients and partners was comparable to that of the reference groups a year after start of chemotherapy, patients even reported better physical functioning at that time. These findings support earlier retrospective studies in testicular cancer survivors and their spouses that also reported few long-term effects in psychosocial functioning in the group overall, but that identified a small group that remains distressed (16;34;35). Little correspondence was found in the functioning of the partners. Clinicians can be reassured that the effect of disseminated testicular cancer on the quality of life of patients and their partners seems to be temporary. However, a minority does seem to need clinical attention for stress response symptoms.

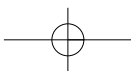
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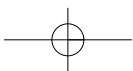
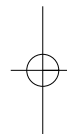
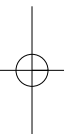
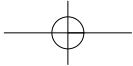
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**chapter 6 self esteem, social
support, and mental health in
survivors of testicular cancer:
A comparison based on
relationship status**

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Introduction

Testicular cancer mainly affects young men aged between 20 and 40 years of age, most men are around 30 years of age when they get diagnosed. This disease strikes men in an important phase of life, which is often characterized by the start of a career, committing to a partner and starting a family. Since 1980, the survival of patients with testicular cancer is extremely good, with a cure rate of at least 90%, owing to the use of cisplatin-based polychemotherapy (1-3). Consequently, increasing numbers of men are survivors of testicular cancer.

Because testicular cancer mainly affects young men, a relatively large percentage of this group is likely to be single at diagnosis. A study in married and unmarried patients with cancer during active treatment showed that a higher percentage of unmarried patients reported higher levels of psychological distress, and more negative thoughts and feelings (e.g., reduced self-esteem or body image problems) than their married counterparts (4). Quality of life has been studied extensively in patients with testicular cancer and survivors (5;6). Surprisingly, psycho-oncological research has paid little attention to single testicular cancer survivors. To our knowledge, only 1 study has been performed that focused on this particular group (7). This study reported that 10 of the 28 respondents believed their medical history would pose a problem for a married future. They thought that the experience with testicular cancer would concern a potential spouse. A more recent qualitative study in survivors of testicular cancer on the motivations to have a prosthesis also showed specific issues for single men. The survivors who chose to have a prosthesis motivated the intervention with reasons like concerns about appearance and the wish to conceal the loss of a testicle, particularly in a new sexual relationship (8). It might very well be the case that single patients with testicular cancer are confronted with specific issues at diagnosis as well as when they continue with life after completion of treatment. It would be of interest to explore whether single testicular survivors face specific challenges.

Concern about appearance, reduced self esteem or finding a partner are not the only areas in which single survivors might have different experiences than survivors in a steady relationship. They might evaluate the social support they receive as different. Social support has been studied extensively as a psychological resource to handle stressful life events (9), also specifically, in patients with cancer and survivors (10). Reviews on social support show that the perception of receiving social support, especially emotional support, is directly related to better physical and mental health. Moreover, the simplest and most powerful measure of social support appears to be whether a person has an intimate, confiding relationship, usually with a spouse or lover (9;11). Research in general has shown a different social support pattern for men than for women. Men appear to rely mostly on their partner or wife, whereas women depend on others like family and friends also (12;13). In patients recently diagnosed with cancer, it was found that male patients with cancer were much more likely to have only one confidant with whom they shared concerns than female patients with cancer, who used

a wider social network (14). There is also evidence that support provided by the intimate partner can not be compensated for by support from other sources (15). Single survivors of testicular cancer might lack this main source of social support, which can possibly affect their mental health in a negative way.

Besides the external resource of social support, patients with cancer can benefit from internal resources as well, such as self-esteem. Self-esteem is defined as satisfaction with oneself or as the attitudes and feelings one has towards oneself (16). It may be that single survivors report lower self-esteem as a result of possible insecurities about their sexuality or physique than survivors who have a partner. Approximately 5% to 10 % of the relationships of survivors of testicular cancer end in a divorce, with the cancer as a significant factor in triggering the break up (5). Therefore, part of the group of survivors of testicular cancer will establish a new relationship after treatment and follow-up has ended.

A recent study on marital and sexual satisfaction in survivors of testicular cancer and their spouses showed that survivors who developed a relationship after completion of treatment had less sexual satisfaction than both a control group of men and survivors who had the same partner as at diagnosis (17). This result might indicate an underlying vulnerability for sexuality in men who do not have a steady relationship at diagnosis. Going through the experience of cancer together has strengthened the relationship and increases levels of intimacy (18;19) which might protect against negative consequences of disease and treatment. Besides that, emotional support (e.g., from a spouse) can help to restore self-esteem or reduce feelings of personal inadequacy (10). Patients with cancer and young adult survivors of childhood cancer had similar levels of self-esteem as the general population (20;21). However, it might well be the case that there are differences in self-esteem in the total group of survivors of cancer. We will explore this idea in a group of survivors of testicular cancer who differ on relationship status. These men are likely to have the same side effects of the experience with cancer, but the difference in relationship status might result in different psychosocial functioning.

The aim of the study was to examine social support, self-esteem and mental health in single survivors of testicular cancer, those with a continuing relationship from time of diagnosis (relationship during testicular cancer) and those with a more recent partner (relationship after testicular cancer). The following questions will be addressed: (1) Are there differences between these groups in support received, in satisfaction with the amount of support, in self-esteem or in mental health?; and (2) Are social support and self-esteem predictors of mental health in the 3 groups?

Patients and methods

Procedure

All men treated for testicular cancer between 1977 and 2002 at the University Medical Centre Groningen in the Netherlands, were contacted in writing and invited to participate in a

questionnaire survey on quality of life. Exclusion criteria were diagnosis within the last 6 months and age younger than 18 years. A total of 702 men received written information explaining the aim of the study and an invitation to participate. The Medical Ethics Committee of the Groningen University Medical Centre approved the study.

Participants

A total of 354 men (50%) agreed to participate in the study. Analyses showed that non-participating survivors of testicular cancer did not differ from participants in age, age at diagnosis or type of treatment received. Of the 354 survivors, 299 (84%) were married or cohabiting at the time of study. Of these survivors, 40 started their relationship after they had completed treatment, and their current partners had not been present at diagnosis. Men who did not have a steady partner at diagnosis and remained single were considered singles. Of the 354 survivors 40 appeared to be single, of whom 16 (40%) were living with their parents, and 24 (60%) were living alone. A random selection was made of the survivors with a relationship during testicular cancer through the Statistical Package for Social Sciences (SPSS 12), to match singles and survivors with a relationship in sample size, and age, using random samples in 4 age cohorts. This resulted in a group of 49 survivors with a relationship during testicular cancer; 1 participant in the original random selection of 50 survivors did not complete one of the relevant questionnaires and was therefore excluded (Table 1).

Questionnaires

Data were obtained on various demographic aspects: age, employment status, and duration of the relationship. Employment status could be indicated as full time job, part-time job, housekeeping, student, unemployed, unable to work, or retired. Information was also obtained from the survivors on the date of diagnosis and type of treatment received. Type of treatment could comprise: orchiectomy (removal of the affected testicle) alone, orchiectomy with retroperitoneal lymph node dissection, orchiectomy and chemotherapy, orchiectomy and chemotherapy and resection of residual retroperitoneal tumor mass or orchiectomy and radiotherapy.

To measure social support the Social Support List was used. This self-report questionnaire has had good construct validity and high reliability (22). Respondents were asked to indicate the amount of support they receive (supportive interactions [SSL-I]), the extent to which support received matched the extent of desired support (dissatisfaction with support) and the amount of negative interactions they received (e.g., criticising or interfering). The SSL-I and dissatisfaction with support were measured through the same 34 items addressing social situations. The questions begin with "Do people ever ..." and end with, for example "show you affection; cheer you up; pay you a compliment, offer help during difficult times". Answers were related to all the people respondents associate with, such as relatives, friends, acquaintances and colleagues. Answers for supportive interactions were given on a 4-point

scale, ranging from: 'seldom or never' (1), 'now and then' (2), 'regularly' (3) and 'very often' (4). A higher score indicated more support. Reliability for supportive interactions in the present study was high. The Cronbach alpha for the singles was 0.95, for survivors with a relationship during testicular cancer 0.92, and for survivors with a relationship after testicular cancer 0.91.

Answers for dissatisfaction with support were given on a 4-point scale, ranging from: 'I miss it, I would like it to happen more often' (1), 'I do not really miss it, but it would be nice if it happened a bit more often' (2), 'just right, I would not want it to happen more or less often' (3), and 'it happens too often, it would be nice if it happened less often' (4). Scores for dissatisfaction were recoded, and a higher score indicated a greater dissatisfaction with support. Reliability for dissatisfaction in the present study was high. The Cronbach alpha for the singles was 0.93, for survivors with a relationship during testicular cancer 0.92, and for survivors with a relationship after testicular cancer 0.89. negative interactions were measured through 7 items (e.g., "Do people ever treat you unjustly; blame you, make unreasonable demands etc."). Items were scored on the same 4-point scale as described for the SSL-I. Scores were recoded so that a higher score indicated less negative interactions. Reliability for negative interactions in the present study was good. The Cronbach alpha for the singles was 0.76, for survivors with a relationship during testicular cancer 0.75 and for survivors with a relationship after testicular cancer 0.76.

Self esteem was measured with the Dutch version of the Rosenberg self esteem scale, a widely used, reliable and valid measure (16;23). The Rosenberg self-esteem scale measures the overall sense of being capable, worthwhile, and competent. The questionnaire consists of 10 items, measured on a 4-point scale varying from 'I totally agree' (1) to 'I totally disagree' (4). There are 5 items that measure positively formulated self-esteem (e.g., 'I feel satisfied with myself') and 5 items that measure negatively formulated self-esteem (e.g., 'I feel I do not have much to be proud of'). After recoding the negatively formulated items, a total score was computed, with a possible range from 10 to 40. Lower scores indicate more self-esteem. The Cronbach alphas for the total score were 0.91 for singles, 0.82 for survivors with a relationship during testicular cancer, and 0.90 for survivors with a relationship after testicular cancer.

The subscale mental health of the Dutch version of the RAND-36 (24) was used to measure psychological functioning. The RAND-36 is an internationally used valid and reliable generic self-report questionnaire to assess Quality of Life (25). After recoding and transformation of the 5 items, scores could range from 0 to 100. Higher scores indicated better mental health. Reliability in the present study was good. The Cronbach alphas were 0.78 for singles, 0.74 for survivors with a relationship during testicular cancer and 0.83 for survivors with a relationship after testicular cancer.

Statistical analyses

Student *t*-tests were performed to examine comparability of the age and size matched random sample and the whole group of survivors with a relationship during testicular cancer. A dichotomous variable was created for employment status, with a full time job and part-time job indicating being employed for wages (0) and housekeeping, student, unemployed, unable to work, or retired indicating being not employed for wages (1). Analysis of Variance was computed to compare the three groups on age and time since diagnosis. An independent *t*-test was performed to compare duration of the relationship between survivors with a relationship during testicular cancer and those who developed a relationship after testicular cancer. Chi-square tests were performed to compare the 3 groups on type of treatment received and employment status. Repeated independent samples *t*-tests were performed to compare mean scores of the groups. An effect size was calculated using the Cohen *d* to assess the clinical significance of differences found. Effect sizes were computed with the formula: mean group 1 minus mean group 2 / pooled standard deviation (SD) of groups 1 and 2. Effect sizes < 0.20 indicate negligible differences, effect sizes between 0.20 and 0.50 indicate a small difference, and those between 0.50 and 0.80 a moderate difference. A large effect size (>0.80) can be seen as a clinically important difference (26;27). To compare the mental health of survivors to that of a reference group of men, reference scores were used from the Dutch manual for the RAND-36. These comprised the mean scores from a group of 691 non-selected men from a random representative sample of 1063 persons aged 18 years and older from the population register of a municipality in the north of The Netherlands with 108,000 inhabitants. The mean age of the persons in the total random sample was 44.1 years (range 18-89 years) (24). To investigate differences between the survivors and the reference group, independent *t*-tests were performed. Pearson's correlations were computed to examine relationships between the study variables. There were 3 separate linear regression analyses performed with mental health as dependent variable, and social support and self esteem as predictors.

Results

Preliminary

As was planned, the random sample and the total group of survivors with a relationship during testicular cancer, including the random sample, differed in age as was expected (mean total group = 46.2 years (SD = 11.6); $t = 3.2$, $p < 0.01$), but not in scores on time since diagnosis, supportive interactions, negative interactions, dissatisfaction with support, mental health, and self-esteem.

Descriptives

Singles, survivors with a relationship during testicular cancer and survivors with a relationship after testicular cancer had a similar age, but Analysis of variance showed that they differed in

time since diagnosis ($F=7.2$, $p<0.001$). Additional Scheffé test showed that survivors with a relationship after testicular cancer had a significantly longer time since diagnosis than singles ($p<0.01$) and survivors with a relationship during testicular cancer ($p<0.05$). Independent t -test showed that survivors with a relationship after testicular cancer had a relationship of shorter duration than survivors with a relationship during testicular cancer. The 3 groups differed in employment status (Chi-square test = 9.4, $p<0.01$), but different treatment modalities were evenly divided among the groups (Chi-square test = 3.4, $p<0.01$) (Table 1).

Table 1 Sociodemographics and treatment related variables

	Single <i>n</i> = 40		Relationship during TC <i>n</i> = 49		Relationship after TC <i>n</i> = 40	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
Age (yrs)	38.8	(12.9)	40.4	(11.5)	40.0	(8.5)
Range	19 - 76		23 - 73		24 - 55	
Time since diagnosis * (yrs)	8.3	(6.1)	9.3	(7.0)	13.6	(5.7)
Range	1 - 23		1 - 24		1 - 24	
Duration relationship (yrs)			14.2	(11.1)	7.5	(5.4)
Range			1 - 48		1 - 21	
	N	%	N	%	N	%
Type of treatment						
Orchiectomy	10	25	13	27	11	28
Orchiectomy & RPLND	1	2	5	10	3	7
Orchiectomy & CT	5	12	6	12	5	13
Orchiectomy, CT & RRRTM	15	38	13	27	18	45
Orchiectomy & RT	9	23	12	24	3	7
Employment status ⁺						
Employed for wages	24	60	44	90	30	75
Not employed for wages	16	40	5	10	10	25

RPLND retroperitoneal lymph node dissection, CT chemotherapy, RRRTM resection of residual retroperitoneal tumor mass, RT radiotherapy. * ANOVA, $p<0.001$; + Chi², $p<0.01$

Differences in supportive interactions, dissatisfaction with support, negative interactions, self-esteem and mental health

Separate independent samples *t*-tests showed that singles reported more dissatisfaction with support ($t=2.2$, $p<.05$; effect size 0.48 (confidence interval (CI) 0.05-0.90)), less self-esteem ($t=3.8$, $p<.001$; effect size 0.83 (CI 0.40-1.27)) and worse mental health ($t=-2.3$, $p<.05$; effect size -0.50 (CI -0.92 —0.08)) than survivors with a relationship during testicular cancer. Singles also reported more dissatisfaction with support than survivors with a relationship after testicular cancer ($t=1.9$, $p<.05$; effect size 0.46 (CI 0.01-0.90)). Survivors with a relationship during testicular cancer reported more self-esteem ($t=-2.2$, $p<.05$; effect size -0.50 (CI -0.92—0.07)) and better mental health ($t=2.5$, $p<.05$; effect size 0.55 (CI 0.12-0.98)) than survivors with a relationship after testicular cancer (Table 2). Independent *t*-tests showed that singles ($t=2.6$, $p<.01$) and survivors with a relationship after testicular cancer ($t=3.0$, $p<.01$) reported a worse mental health than a reference group of men (mean = 79.4, $sd = 17.3$). Survivors with a relationship during testicular cancer reported similar mental health as a reference group of men.

Social support, self esteem and relationship status as predictors of mental health according to relationship status

Pearson correlations showed that age, time since diagnosis and duration of the relationship, for those survivors who have a relationship, were not related to mental health. Independent

Table 2 Social support, mental health, and self esteem

	Single		Relationship during TC		Relationship after TC	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
Supportive interactions	69.3	(16.2)	70.4	(12.8)	73.5	(11.3)
Dissatisfaction with support	45.6	(10.7)	40.7 *	(9.9)	41.4 #	(7.1)
Negative interactions	23.9	(3.0)	24.7	(2.5)	23.7	(2.6)
Self esteem	19.7	(4.9)	16.1 **	(3.7)	18.2 +	(4.7)
Mental health	72.5	(15.6)	79.7 *	(13.1)	72.2 +	(14.0)

Comparison singles vs relationship during TC: * $p<.05$, ** $p<.001$

Comparison singles vs relationship after TC: # $p<.05$

Comparison relationship during vs relationship after TC: + $p<.05$

Table 3 Correlations between self esteem, social support, and mental health

	Self esteem	Supportive interactions	Dissatisfaction with support	Negative interactions
Mental health	-.35*	-.08	-.52**	.28
	<i>-.54***</i>	<i>-.17</i>	<i>-.49***</i>	<i>.46**</i>
	<i>-.38*</i>	<i>.07</i>	<i>-.31</i>	<i>.47**</i>

Correlations in the singles group are in **bold**, in the group survivors with a relationship during TC in *italic* and in the group of survivors with a relationship after TC in regular figures. * p<0.05 ** p<0.01 *** p<0.001

samples *t*-test showed no difference in mental health according to employment status. For singles, self-esteem and dissatisfaction with support were significantly related to mental health, indicating that singles who reported more self-esteem and less dissatisfaction with received support reported better mental health. For survivors with a relationship during testicular cancer, self-esteem, dissatisfaction with support and negative interactions were related to mental health, indicating that survivors with a relationship during testicular cancer reporting more self esteem, less dissatisfaction with support and few negative interactions reported better mental health. Survivors with a relationship after testicular cancer who reported few negative interactions and more self-esteem reported better mental health (Table 3).

There were 3 separate regression analyses performed to examine the predictive power of self-esteem, dissatisfaction with support, and negative interactions on mental health. Because the level of supportive interactions, age, time since diagnosis, duration of the relationship, and employment status were not related to mental health in all 3 groups, these factors were not included in the analyses. For singles, 29% of the variance in mental health was explained ($F=4.8$, $p<.01$) with dissatisfaction with support ($\beta = -.52$, $p<.01$) having a significant independent effect while the effect of self-esteem did not reach significance. For survivors in a relationship during testicular cancer 38% of the variance in mental health was explained ($F=8.4$, $p<.001$). Self-esteem appeared to have a significant independent effect ($\beta = -.32$, $p<.05$), whereas dissatisfaction and negative interactions did not uniquely affect mental health in this group. For survivors with a relationship after testicular cancer, 38% ($F=6.4$, $p<.01$) of the variance in mental health was explained. Both self-esteem ($\beta = -.33$, $p<.05$) and negative interactions ($\beta = .45$, $p<.01$) had significant unique effects.

Discussion

The aim of the present study was to explore differences in self-esteem, social support and mental health in 3 groups of survivors of testicular cancer: singles, those with the same partner as at diagnosis, and those with a partner they met after completion of treatment. In addi-

tion, the predictive effects of self-esteem and social support on mental health in these 3 groups were investigated. Being single or having a steady partner did not influence the perception of the amount of social support (supportive and negative interactions) received by survivors of testicular cancer. It might be that single survivors of testicular cancer derive social support from other sources, like family and friends, which levels out the support they may miss from an intimate partner. The questionnaire used for social support did not differentiate between sources of support. Answers were related to all the people the respondents associated with, which underlines the idea of using different sources of social support. It did appear that singles are less satisfied with the support they receive than survivors with the same partner and those with a more recent partner. Although singles had the same quantity of support, they were less satisfied. This finding would suggest that their needs for support were not met. Survivors of testicular cancer with a partner might have support from their spouse that is more in line with their need. Previous research showed that for men, the support received by a spouse is experienced as most important (12;13;15).

Self-esteem was not similar among the investigated groups. Survivors with the same partner as at diagnosis reported the highest self-esteem, followed by survivors with a partner they met after completion of treatment. Singles reported the least self-esteem. According to the effect size, the difference between singles and survivors with the same partner they had at diagnosis was clinically significant, meaning that it is noticeable in daily life as well. The general idea is that social support enhances self-esteem (9-11). However, in our group of survivors of testicular cancer, social support did not differ between groups but self-esteem did. The dissatisfaction with support that singles reported the most, might have contributed to the lower self-esteem in this group.

We also wanted to explore whether social support and self-esteem are predictors of mental health in these groups. As was the case for self-esteem, the 3 groups differed in mental health. Survivors who established a relationship before the testicular cancer reported the best mental health, followed by the other 2 groups that did not differ from each other. For singles, only dissatisfaction with support predicted mental health, while this was not a predictor for the other two groups. Again, a possible explanation might lie with different sources from which these survivors receive support. It seems that the most appreciated source of support for men is the spouse. Support from others might not be as effective in increasing mental health as that from an intimate partner. Self-esteem was a predictor for mental health in survivors with the same partner as at diagnosis and those with a partner they met after completion of treatment. A surprising result was that even though singles reported the worst self-esteem, it was not a predictor for their mental health. For survivors who met their partner after completion of treatment, the level of negative interactions they received also predicted mental health, which was not the case in the other 2 groups. It was reported that couples who faced cancer together have a relationship that is strengthened (19;28). However, the partners who developed a relationship with the survivors after completion of treatment were

reported to have more problems with psychological quality of life domains than the partners who were present throughout the diagnosis and treatment process, and a reference group of women (29). Perhaps this result is a reflection of a relationship with more stressful or negative interactions.

Compared to a representative reference group of Dutch men, both singles and survivors with a relationship that started after completion of treatment reported lower mental health. Survivors with the same partner as at diagnosis reported the same mental health as the reference group. It looks like survivors with the same partner have better adjustment to the diagnosis and treatment of cancer, and regain a normal level of mental health. The dissatisfaction of singles with the social support they receive and the impact of negative interactions in survivors with a relationship after testicular cancer might explain why they both have a lower level of mental health than the reference group.

Self-esteem, dissatisfaction with support, and amount of negative social interactions were related to mental health, but in different ways for each group of survivors of testicular cancer. Surprisingly, for all 3 groups supportive interactions were not predictors of self-esteem or mental health. Negative interactions and positive social interactions can occur simultaneously. It has been found that negative interactions are often a stronger predictor of psychological well-being than positive interactions in general (30), in patients with cancer (31), and in fathers of a child with cancer (32). This result seems to be the case in the current study group also. A possible explanation for this finding might lie in the fact that negative interactions are more rare and, therefore, have a greater impact (33).

It is noteworthy that this study has some limitations. First, the response rate was 50%. Non-response could affect the results and the generalizability of the findings. However, the study group represents a large number of survivors of testicular cancer that did not differ from non-participants in age, age at time of diagnosis, or type of treatment received. Second, because of the retrospective design, this study does not provide insight into the possible consequences of testicular cancer on relationship status in patients over time. Relationships may be negatively affected by the diagnosis of testicular cancer. Possible consequences, such as infertility and sexual problems, may lead to an extent of marital problems that partners decide to divorce. This topic should be addressed in future research using a prospective design.

Conclusions

Self-esteem and mental health differed between single survivors of testicular cancer, survivors with a continuing relationship since diagnosis and survivors who met their partner after treatment completion. The trend seems to be that survivors with the same partner as at diagnosis have the highest level of functioning, they reported the most self-esteem and the best mental health. Survivors of testicular cancer who developed a relationship after completion of treatment did have better scores overall than singles, but mental health was compa-

able to that of singles, and lower than that of a reference group of men. This result might suggest that they both have issues that are negatively related to their psychological well-being. Previous research showed no difference in self-esteem between (cured) patients with cancer and the general population, but this study showed differences in a group of survivors of cancer with the same diagnosis. Men who are single when they are diagnosed with testicular cancer and remain single are a vulnerable group when it comes to self-esteem and mental health. Perhaps certain negative issues remain relevant when the survivor meets a partner and starts a relationship, since this group, too, reported lower mental health. 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. In particular, leave room and opportunity to discuss concerns they have regarding their future.

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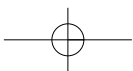
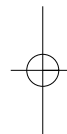
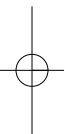
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**chapter 7 sexual function,
depressive symptoms and marital
status in testicular cancer
patients: a longitudinal study**

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Introduction

Testicular cancer is rare (1% of new cancer diagnoses in men), but the most frequent malignancy in young men aged between 15 and 40 years. The highest incidence lies around 30 years of age (1;2). Testicular cancer is highly curable, with approximately 85% of men surviving the disease (3). Sexual functioning in testicular cancer patients and survivors has received attention before. This is not surprising, as this type of cancer involves an organ associated with sexuality, and strikes at a young age when sexuality is of great importance. Testicular cancer patients can experience sexual problems after diagnosis and completion of treatment which can strongly affect global quality of life (4).

Two review studies on sexual functioning in men who were treated for and survived testicular cancer reported that a varying percentage of testicular cancer survivors suffered several physical sexual problems such as ejaculatory failure (29%-44%), orgasmic problems (10%-20%), and erectile dysfunction (approximately 10%) (5;6). According to more recent studies the prevalence of erectile dysfunction after testicular cancer is similar to that found in the general population (4;7). In addition to physical sexual problems, a considerable percentage of survivors also report psychosexual dysfunction after treatment like decreased desire (7%-20%), decreased sexual activity (9%-24%) and dissatisfaction (5%-20%). Sexual dysfunction was reported to persist for up to two years after treatment, after which functioning seems to recover (5;6). According to the reviews, the majority of studies on sexual functioning after testicular cancer have methodological shortcomings. Studies differ widely in variables included and outcomes measured, making comparison difficult. In addition, only a limited number of studies used standardized questionnaires, normative data or measured sexual functioning prospectively. A more recent study addressed sexual functioning in testicular cancer survivors and compared this to functioning in a norm group (8). Results indicated that survivors experienced more problems with sexual drive, erection and ejaculation than men in the norm group. However, young survivors (20-39 years) reported more sexual satisfaction than their normative counterparts. It remains unclear why some survivors develop and continue to have sexual problems, while others do not. It is therefore useful to gain insight to possible risk factors for the development of sexual dysfunction.

A possible risk factor might be type of treatment. Hormonal, vascular and nervous systems seem to be disturbed by chemotherapy which may result in sexual dysfunction. Men who underwent a retroperitoneal lymph node dissection (RPLND) after chemotherapy reported ejaculatory dysfunction. Fortunately, this negative side effect was considerably reduced since modification of RPLND techniques about 25 years ago into resection of residual retroperitoneal tumor mass only (RRRTM) (9). Psychosexual functioning appears to be reduced independently of type of treatment (5;10-13).

A second risk factor may be the relationship status of patients. In general, married men appear to experience a better quality of life than single men, and this might include sexual functioning as well (14). Since testicular cancer patients are relatively young, a significant

number will not yet have established a steady relationship and is therefore single. Most studies indicated that around 70% of participating testicular cancer survivors was in a committed relationship when diagnosed (15). A review study indicated that little attention has been paid to the effect of relationship status on functioning in testicular cancer patients and survivors (16). The few studies that addressed this subject showed that testicular cancer survivors in relationships established after completion of treatment reported less sexual satisfaction than men in the general population, and than testicular cancer survivors who had the same partner as at time of diagnosis (17). It was also found that testicular cancer survivors who did not have a partner were more likely to report sexual problems, defined by drive, erection and ejaculation problems, or a satisfaction problem compared to survivors who did have a partner (18). Contradictory to these findings was the finding that sexual functioning in testicular cancer patients was similar in men with a partner and singles. However, married men seemed somewhat more worried about changes in their appearance and attractiveness, and an earlier study found that 24% of married survivors perceived themselves to be less attractive as a result of their treatment (19;20). These contradictory findings make it of interest to take relationship status as a risk factor into account for sexual dysfunction.

A third risk factor may be depression. It has been suggested that the emotional impact of testicular cancer may be a more important predictor of sexual dysfunction than objective physical and treatment aspects (5;13). Psychological responses to diagnosis and treatment should therefore be taken into account when studying sexual functioning. However, very little attention has been paid to the relationship between emotional distress and sexual dysfunction in this group (6). Depressive symptoms are prevalent in cancer patients, with reported rates varying between 15%-24% (21;22). Depression appears to be prevalent in 9-11% of testicular cancer survivors up to 5 years after treatment completion (23) and is unrelated to age at diagnosis, type of treatment or marital status at diagnosis. Depression is well known to be related to sexual dysfunction, with the majority of (not cancer-related) depressed patients reporting sexual dysfunction. It is associated with decreased libido, decreased frequency of intercourse, erectile dysfunction and delayed or absent orgasm, independent from use of antidepressant drugs (24). A study on long-term testicular cancer survivors (median number of years since treatment 3.9) showed that severely impaired sexual functioning was related to more depression and fatigue (12).

To advance on existing research, the present two-center study focused on sexual functioning in testicular cancer patients during the first year after orchiectomy (removal of the affected testicle), using standardized questionnaires. The effect of relationship status, type of treatment and depressive symptoms on sexual functioning were taken into account. Main research aims were to examine:

- the trajectory of sexual functioning during the first year after removal of the affected testis
- differences in sexual functioning on the basis of type of treatment received and relationship status
- the effect of depressive symptoms on sexual functioning concurrently and prospectively.

Methods

Patients and procedure

This study was part of a larger study on the possible negative effects of chemotherapy after testicular cancer. As chemotherapy is a treatment option after diagnosis of non-seminomatous testicular tumors, only patients with this diagnosis were included. Two patient groups diagnosed with a non-seminomatous testicular tumor were approached for participation. The first group consisted of all patients referred to the University Medical Center Groningen (UMCG) in The Netherlands for treatment between April 2001 and March 2004. Exclusion criteria were age younger than 18 years at study entry, a psychiatric illness or history involving formal thought disorders, insufficient command of the Dutch language, prior neurologic illness, and previous treatment for cancer. The study was approved by the Medical Ethics Committee of the University Medical Center Groningen. The second group consisted of all patients consecutively visiting the MD Anderson Cancer Center (MDACC) in Houston, Texas, United States of America for treatment between December 1999 and December 2002. The study was approved by the Institutional Review Board (IRB) of the MDACC. Exclusion criteria were age younger than 18 years at study entry, a psychiatric illness or history involving formal thought disorders, insufficient command of the English language, inability to give informed consent, prior neurologic illness, and an extragonadal germ cell tumor.

Orchiectomy is both therapeutic and diagnostic: a conclusive diagnosis of testicular cancer results from pathology assessment of the removed testicle. Therefore, the study was introduced to patients after orchiectomy in both institutions. Patients received oral and written information about the study from co-workers of the study, together with an informed consent form. Patients who agreed to participate, received a self-report questionnaire at three time points: after orchiectomy but before the start of chemotherapy (T1), immediately after chemotherapy completion or three months after T1 (T2), and one year after T1 (T3). At both hospitals T1 and T2 questionnaires were completed in the hospital. At the MDACC patients filled in the T3 questionnaire at the hospital as well, at the UMCG T3 questionnaire and a prepaid return envelope were sent to the patients' home address.

Instruments

Information on age, educational level, daily occupation, proposed type of treatment and relationship status (dichotomized into the categories 'with a partner' (married or in a committed relationship) and 'single') were collected at T1. Daily occupation was dichotomized into the categories 'employed for wages' (including self employed) and 'not employed for wages' consisting of students, being unemployed, and being unable to work. On T3, information on type of treatment received was retrieved from the patients' medical files. Dutch educational level was measured on a 7-point scale: 'Elementary school' (1), 'Lower technical/vocational degree' (2), 'High school -low level' (3), 'Middle level technical/vocational

degree' (4), 'High school - high level' (5), 'Higher technical/vocational degree' (6), and 'University degree' (7). American educational level was measured on a 7-point scale also, using the following levels: 'Never received a high school diploma/GED' (1), 'High school diploma/GED' (2), 'Technical/vocational degree' (3), 'Some college level credits or 2 years college degree' (4), 'Bachelors degree' (5), 'Masters degree' (6), and 'M.D., Ph.D., or advance degree' (7). Because both countries measured education according to a 7-point scale, and higher scores indicated more years of education we treated education level as a continuous variable. Type of treatment consisted of orchiectomy only, orchiectomy and chemotherapy, or orchiectomy, chemotherapy and resection of residual retroperitoneal tumor mass. Patients of the UMCG group received four cycles of bleomycin, etoposide and cisplatin (BEP), with a three-week interval between each cycle. Chemotherapy regimen in the MDACC group ranged from 1 to 7 cycles, depending on stage, tumor markers, and response. BEP was the most commonly administered regimen, but several patients received CISCA/VB (cyclophosphamide, adriamycin, cisplatin, vinblastine, and bleomycin), or BOP (vincristine, bleomycin, and cisplatin)/CISCA/POMB (vincristine, methotrexate, and bleomycin) /ACE (etoposide, actinomycin, and cyclophosphamide). Strategies for treatment following chemotherapy are comparable at the UMCG and the MDACC. All patients with disseminated testicular cancer and residual disease after chemotherapy with masses > 1 cm on a CT scan underwent an exploratory laparotomy and resection of residual retroperitoneal tumor mass (RRRTM) (3). All patients with a mature component in the primary testicular tumor underwent an exploratory laparotomy as well to ensure that all potential metastatic disease was resected (25).

Sexual functioning was measured using the International Index of Erectile Function (IIEF), a widely used, multi-dimensional self-report instrument for the evaluation of male sexual function (26;27). The IIEF consists of 5 subscales: erectile function (6 items), orgasmic function (2 items), sexual desire (2 items), intercourse satisfaction (3 items), and overall satisfaction (2 items), and provides a total score (sum of all items). Normscores are available from 109 male volunteers (mean age 55 years, range 29-76) without a history of sexual dysfunction. Items were scored with different value labels on a five- or six-point scale, and 9 items were scored 0 when the patient had not been sexually active. A mean score for each subscale was calculated and higher scores indicated better functioning. Reliability of the IIEF in the UMCG group was good for all subscales (alphas ranged from 0.86 to 0.98 over the three measurement times). Reliability for the IIEF in the MDACC group was good for all subscales (alphas ranged from 0.86 to 0.95 over the three measurement times), except for the alpha for orgasmic function at T3 which was somewhat less good (0.69).

Depression was measured with the CES-D, a twenty-item questionnaire that measures depressive symptoms during the past week. Items are scored on a 4 point scale ranging from seldom or never [0], sometimes or a little [1], regularly [2], to most of the time or always [3]. Scores are summed, resulting in a possible total score ranging from 0 to 60. A score of 16 or

above suggests clinically significant depressive symptoms. The CES-D shows good internal validity and reliability (28), also in cancer patients (22). In the present study Cronbach's alphas for the UMCG group ranged from 0.89 – 0.91, and for the MDACC group from 0.88–0.91.

Statistical analyses

Independent measures t-tests and Chi-square test were performed to examine differences in sociodemographics and type of treatment between patient groups according to nationality and relationship status. The cut off score of the CES-D was used to identify patients who were experiencing clinically significant depressive symptoms. Repeated measures analyses of variance were computed to examine change over time in the five domains of sexual functioning and depressive symptoms; firstly with relationship status and secondly with type of treatment (3 groups) as between-groups factor. Relevant covariates were entered to control for differences between groups. Independent t-test were performed to examine differences between sexual functioning of respondents at T3 and that of the normgroup. Effect sizes were calculated using Cohen's d to assess the clinical significance of differences found over time and of comparison with norm. Effect sizes lower than .20 indicate negligible differences, effect sizes between .20 and .50 indicate a small difference, and those between .50 and .80 a moderate difference. A large effect size ($\geq .80$) can be seen as a clinically important difference (29).

Pearson correlations were used to examine relationships between sexual functioning and depressive symptoms, concurrently (within time, T1 depressive symptoms with T1 sexual functioning etc.) and prospectively (T1 depressive symptoms and T2 and T3 sexual functioning, controlling for T1 sexual functioning). By controlling for levels of the dependent variable at T1, inferences can be made about the direction of the causal influence.

Results

Population

Of the 70 patients diagnosed with testicular cancer during the inclusion period in the Netherlands, 6 (8%) did not meet the inclusion criteria. Fifteen patients decided not to participate (response = 77%). After T1, 9 of the 49 (18%) patients dropped out of the study. Which means that complete data were available from 40 out of 64 eligible patients. At the MDACC, all patients with a possible diagnosis of testicular cancer (n=280) seen in the genitourinary clinic were systematically screened. Of these, only 100 were eligible based on our eligibility requirements. Other reasons include not being newly diagnosed, extragonadal primary, brain metastases, too old or young, bilateral tumors, and positive history of a major head injury. Seventy six patients consented to participate of whom 53 completed all assessments (response = 76%, 30% drop-out). In total, data of 93 patients were analyzed.

Sociodemographic and treatment related variables

Mean age of all patients at T1 was 29.4 years (standard deviation (sd) 7.5), ranging from 18 to 50 years. Educational level completed varied from primary school to advanced university degree, most patients (30%) had a technical vocational degree or some years of college. Of the patients, 74 (80%) were employed for wages. Of the 19 who were not, 14 were students, 3 were unemployed, and 2 were unable to work. At T3, twenty-four patients (26%) had been treated with orchiectomy alone, 41 (44%) with orchiectomy and chemotherapy, and 28 (30%) were treated with additional RRRTM. More than half of the patients were married or cohabiting, 39% was single. Singles appeared to be younger ($t = -4.0$, $p < .001$) and more often unemployed (Chi-square = 12.3, $p < .001$) than patients with a partner (Table 1).

Preliminary analyses

It may be that differences exist between Holland and the United States with respect to organization of health care, education and work as well as for social norms regarding dating behaviour and establishing relationships. Analyses showed that relationship status and employment status were comparable in the two countries. Minor differences were found with respect to age (UMCG patients were somewhat younger than MDACC patients ($t = -2.0$, $p < .05$)), educational level (MDACC patients finished higher levels of education (Chi² = 12.8, $p < .05$)), and type of treatment (UMCG patients more often receiving additional abdominal surgery (Chi² = 11.4, $p < .01$)). Repeated measures analyses of variance with between subject factor nationality showed differences in erectile function ($F = 6.2$, $p = .015$), sexual desire ($F = 3.9$, $p = .049$), and overall satisfaction ($F = 12.4$, $p = .001$) at some, but not all time points. There were no significant interactive effects of nationality and time. To account for these differences found and for other potential cultural covariates, a nationality variable was retained in subsequent analyses.

Effect of time on sexual functioning

Significant time effects were found on erectile function, orgasmic function, intercourse satisfaction, overall satisfaction and the total score. Inspection of the mean scores showed that levels of erectile function and intercourse satisfaction were comparable at T1 and T2, but higher at T3. Orgasmic function, overall satisfaction and the total score followed a positive quadratic trajectory, meaning that begin and end scores rise above the center point. Levels decreased between T1 and T2, and increased to an above T1 level at T3. Effect sizes of statistically significant changes over time were negligible indicating that changes were not clinically significant (Table 2).

Effect of relationship status

Repeated measures analysis of variance with between subjects factor relationship status and

Table 1 Sociodemographics at T1 and type of treatment received at T3

	M, N	SD, %
Age (years)	29.4	7.5
range	18 - 50	
Educational level		
1	3	3%
2	14	15%
3	12	13%
4	28	30%
5	23	25%
6	9	10%
7	4	4%
Relationship status		
Single	36	39%
Partner	57	61%
Employment status		
Employed for wages	74	80%
Not employed for wages	19	20%
Type of treatment		
surgery	24	26%
surgery + CT	41	44%
surgery + CT +/- RRRTM***	28	30%
* <i>t</i> -test: $t = -2.0$, $p < .05$		
** Chi-square = 11.4, $p < .01$		
*** CT = chemotherapy, RRRTM = resection of residual retroperitoneal tumormass		

covariates age and employment status, indicated a significant group effect on erectile and orgasmic function, intercourse and overall satisfaction, and the total score but not on level of desire. Singles reported worse functioning than committed patients over the year. Effect size for the difference in intercourse satisfaction was small, and differences in the other domains were negligible (Table 2). There was a significant interactive effect of time and relationship status on sexual desire ($F=7.4$, $p < .01$) and overall satisfaction ($F=7.3$, $p < .01$), indicating that desire and overall satisfaction changed over time in different ways for single and committed patients. Inspection of the mean scores showed that singles reported higher levels of desire at T1 and T3 (not significant) than committed patients, and a comparable level at T2. Singles

Table 2 Descriptives on sexual functioning and repeated measures analyses of time and group effects

	T1 Mean (SD)	T2 Mean (SD)	T3 Mean (SD)	Effect	F	P	Effect size
Erectile function	21.6 (9.7)	21.1 (10.3)	24.1 (7.9)	Time	4.8	.03	.05
				Group: relationship status	26.5	.000	.19
				Group: treatment	0.9	<i>ns</i>	
Orgasmic function *	7.8 (3.5)	6.9 (4.1)	8.4 (3.0)	Time	8.7	.004	.09
				Group: relationship status	6.9	.01	.08
				Group: treatment	2.1	<i>ns</i>	
Sexual desire	6.9 (1.9)	6.8 (2.1)	7.3 (1.7)	Time	3.9	<i>ns</i>	
				Group: relationship status	0.33	<i>ns</i>	
				Group: treatment	1.4	<i>ns</i>	
Intercourse satisfaction	8.2 (5.7)	7.9 (5.8)	10.0 (5.0)	Time	7.7	.007	.08
				Group: relationship status	29.1	.001	.26
				Group: treatment	1.2	<i>ns</i>	
Overall satisfaction *	7.7 (2.3)	7.1 (2.2)	7.9 (1.8)	Time	10.7	.002	.12
				Group: relationship status	10.2	.002	.10
				Group: treatment	1.0	<i>ns</i>	
Total *	53.4 (19.0)	50.3 (21.8)	58.2 (16.0)	Time	7.2	.009	.08
				Group: relationship status	14.4	.001	.16
				Group: treatment	2.0	<i>ns</i>	

* : quadratic

ns: not significant

experienced significantly lower overall satisfaction as compared to committed patients at all measurement times, with the difference being greatest at T1.

Effect of treatment

Repeated measures analysis of variance, with between subjects factor treatment, showed no significant group effect or interactive effect of group and time on any aspect of sexual functioning (Table 2).

Comparison with norm at T3

One year after diagnosis, sexual functioning of patients did not differ from norms, except for one aspect: patients reported less overall satisfaction ($t=2.8$, $p<.01$) than norms (mean=8.6, $sd=1.7$). The clinical relevance of this difference appeared small according to the effect size ($d=-0.4$; 95% confidence interval, $ci: -0.7 - -0.12$). Patients in a committed relationship differed from norms only on intercourse satisfaction: patients reported more satisfaction ($t=-2.2$, $p<.05$) than norms (mean=10.6, $sd=3.9$). The clinical relevance of this difference appeared small according to the effect size ($d=0.33$; $ci: 0.0 - 0.66$). Singles reported worse erectile function ($t=3.3$, $p<.01$) than norms (mean=25.8, $sd=7.6$), less intercourse satisfaction ($t=3.0$, $p<.01$), and less overall satisfaction ($t=2.6$, $p<.01$). The clinical relevance of these three differences were moderate according to effect sizes (erectile function: $d=-0.70$, $ci: -1.08 - -0.34$; intercourse satisfaction: $d=-0.74$, $ci: -1.1 - -0.36$; overall satisfaction: $d=-0.56$, $ci: -0.93 - -0.19$).

Depressive symptoms and sexual functioning

Depressive symptoms were highest at T1 (mean 11.6, $sd 8.9$) and decreased over time (T2: mean 9.9, $sd 8.6$; T3: mean 7.9, $sd 7.8$) ($F=20.6$, $p<.001$). The change over time was however negligible according to the effect size (0.18). At T1, 24 patients (26%) reported clinically significant depressive symptoms, at T2, 14 patients (15%), and at T3, 15 patients (16%) did. Pearson's product moment correlation coefficients between Times 1 and 2 ($r=.58$), Times 2 and 3 ($r=.65$), and Times 1 and 3 ($r=.58$) depressive symptoms were significant and strong. At T1, more single patients (44%) reported clinically significant depressive symptoms than committed patients (14%) ($\chi^2 = 10.7$, $p<.001$), but percentages were not significantly different at T2 (11% and 18% resp.) and T3 (17% and 16% resp.). The percentages of patients reporting clinically significant depressive symptoms did not differ between the two treatment groups at T2 and T3 (treatment was similar for all patients at T1), or between nationalities.

At T1, depressive symptoms were negatively related to 4 of the 6 subscales of sexual functioning: weakly to erectile function ($r=-.27$, $p<.01$), sexual desire ($r= -.22$, $p<.05$) and the total score ($r=-.29$, $p<.01$), and moderately strongly to overall satisfaction ($r=-.36$, $p<.001$). At T2, depressive symptoms were negatively and moderately strongly related to overall sat-

Table 3 Concurrent and prospective relationships between depressive symptoms and sexual functioning

CES-D	Concurrent			Prospective	
	T1	T2	T3	CES-D and T2 sexual functioning	CES-D and T3 sexual functioning
	<i>r</i>	<i>r</i>	<i>r</i>	Partial <i>r</i> [#]	Partial <i>r</i> [#]
Erectile function	-.27**	-.20	-.13	-.02	-.14
Orgasmic function	-.19	-.14	-.03	-.09	-.01
Sexual desire	-.22*	-.17	-.06	-.06	.01
Intercourse satisfaction	-.20	-.13	-.08	-.02	-.04
Overall satisfaction	-.36***	-.37***	-.24*	-.03	-.02
Total	-.29**	-.24*	-.12	.05	-.06

* $p < .05$, ** $p < .01$, *** $p < .001$ [#] controlled for T1 depressive symptoms

isfaction ($r = -.37$, $p < .001$), and negatively weakly to the total score ($r = -.24$, $p < .05$). At T3, one negative weak correlation was found between depressive symptoms and overall satisfaction ($r = -.24$, $p < .05$). No significant prospective effect was found of T1 depressive symptoms on T2 or T3 levels of sexual functioning (Table 3).

Discussion

This longitudinal study focused on functional and psychological sexual functioning in testicular cancer patients during the first year after orchiectomy, and on possible differences in sexual functioning according to relationship status, treatment and depressive symptoms. It appeared that sexual functioning after testicular cancer fluctuates during the first year after orchiectomy, but type of treatment and depressive symptoms are no risk factors for sexual dysfunction. Singles did report more sexual problems than committed men.

Testicular cancer patients experienced changes in all aspects of sexual functioning, except in desire. Apparently, in this group of young male cancer patients, desire in sexual activity seems unaffected by the cancer experience, at least during the first year. The other aspects of sexual functioning changed over the year, but according to different patterns. 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 (which is the ending of chemotherapy cycles for 75% of patients), 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 patients reported improvement to above baseline level after one year. When compared to norm scores, patients only reported less overall satisfaction. Clinical relevance of this decreased satisfaction appeared to be small. However, even though most aspects of functioning were comparable to that of a norm group, this finding may be a cause of concern as the norm group is an average of 25 years older.

The pattern of improvement to above baseline level has been reported before in a study on quality of life of testicular cancer patients, that also included emotional and sexual items (30). It is possible that physical complaints, psychological distress and recuperating from surgery negatively affected sexual functioning, and that functioning improved after the patient was treated and responding well and the immediate threat was over. A comparable pattern was found when testicular cancer survivors were asked to rate their psychological functioning at time of study, and in retrospect prior to treatment and six months after treatment (31). Apparently, both from a retrospective as well as prospective view, patients assess the months following end of treatment as most stressful. It must be noted that even though sexual functioning showed a decrease after treatment, the overall change over the year was not clinically significant according to effect sizes.

The present study showed that type of treatment was unrelated to sexual functioning, which is in line with previous studies on sexual functioning and quality of life of testicular cancer patients (5;7;11;13;16;32). However, in other studies testicular cancer patients reported worse functioning on various quality of life domains, like physical function and fatigue immediately after completion of chemotherapy (30;33). Perhaps increased underlying fatigue, which we did not include in the present study, can explain the decreased orgasmic functioning, overall satisfaction and total sexual functioning at 3 months after orchiectomy. The current study showed that relationship status does play a role in explaining sexual functioning. Single testicular cancer patients reported worse sexual functioning over the year as compared to patients with a partner in all but one aspect, namely desire. Even though differences between single patients and those in a relationship were statistically highly significant, effect sizes indicated that the differences were not clinically significant. It is likely that single men have intercourse less frequently than committed men. Not being sexually active can result in lower scores in the IIEF on erectile functioning and intercourse satisfaction, and that can partly account for the difference between single and committed patients for these aspects. While the desire to be sexually active was the same in both groups (again underlining the idea that desire is unaffected by the experience with cancer), singles evaluated their actual functioning as worse. When compared to a norm group one year after surgery, singles also reported less overall satisfaction, worse erectile functioning, and less intercourse satisfaction. Effect sizes were on the verge of being clinically relevant for the latter two, suggest-

ing that functioning on these aspects is a problem for singles. Men in a steady relationship at time of diagnosis often experience increased intimacy with their partners (17;19;34), possibly buffering negative feelings and consequences of their treatment for testicular cancer. The finding that patients in a relationship reported more intercourse satisfaction than men in the norm group may reflect this increased intimacy. Singles might experience more insecurity about their physical functioning because they miss this intimacy of a relationship. A second factor that may explain the difference between single and committed patients might be fertility distress. Infertility is a main concern for testicular cancer patients and survivors, eventually affecting approximately 30% of survivors (35). Even though sperm banking is quite common before start of treatment, and infertility can be assessed only after trying to actively conceive for one year, concerns about infertility may haunt testicular cancer patients in the first year after diagnosis. The testes are associated with feeling strong and potent, and the possibility of reproductive failure seems to decrease the idea of a masculine identity (36;37). Concerns about possible infertility have been found to negatively affect sexuality and sexual functioning, especially in singles, who might question whether they will find a partner (36). The third possible risk factor for sexual dysfunction examined was depression. Depression was most prevalent directly following orchiectomy, with 26% suffering from clinically elevated levels indicating that they probably need professional care. Later on in the year this percentage dropped to 16 and is comparable to that found in an earlier study (31). Directly following orchiectomy, 44% of the singles reported clinically elevated levels of depressive symptoms as compared to 14% of patients in a relationship, later on in the year no differences were found. Being unmarried was also found to be a risk factor for elevated depressive symptoms in breast cancer patients (38). Single testicular cancer patients might lack the support a partner may offer during the most stressful period of their illness, as men have been found to usually draw the most support from their partner (39).

Shortly after orchiectomy, when depressive symptoms were most prevalent, depression and several domains of sexual functioning were found to be related. Men who experienced more depressive symptoms reported having more erectile dysfunction, less sexual desire, less overall satisfaction, and a lower overall sexual functioning directly following orchiectomy. However, three and twelve months later depressive symptoms were weakly related only to overall sexual functioning. Depressive symptoms also had no predictive power in later sexual functioning. Apparently, depressive symptoms are not a strong risk factor for sexual problems, at least, not in testicular cancer patients.

This study has some limitations. Firstly, no information was available on the functioning of patients who declined to participate. They may have been those who were functioning best or worst, the results may have been biased in either direction. Secondly, although nationality was controlled for in the analyses, it might be that differences in social norms between America and the Netherlands may influence participants' responses to the sexual functioning items. A larger study including patient groups from several countries can address cultural influences on sexuality after testicular cancer better than a two site study.

Major strengths of the study were however the use of a prospective study design, and the use of a standardized, well-validated measure of sexual function. Different designs of studies on sexual functioning generates different findings. It was found earlier that an assessment made by patients retrospectively indicated considerable sexual deterioration after surgery for benign prostatic disease, whereas a prospective assessment showed little impact (40), possibly due to recall bias of the respondents. It is also interesting that when testicular cancer survivors were asked to describe their baseline sexual functioning twice (firstly before start of treatment, secondly at time of study), they evaluated their baseline sexual functioning worse at time of study than they did before the diagnosis (31). This finding could not be supported by our prospective results, that mainly showed significant, but not clinically relevant deterioration.

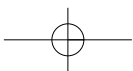
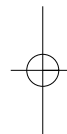
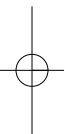
The positive findings of this study was that sexual functioning appeared to have improved one year after orchiectomy and that the decreases found were not clinically relevant. Men in a relationship even reported more intercourse satisfaction than norms. The fact that patients in a relationship experienced similar functioning as the norm group consisting of much older men, and that single patients reported worse functioning than men in the norm group is reason for concern however. Earlier studies showed that impaired sexual functioning appears to remain prevalent in approximately 15% of long-term testicular cancer survivors (41). We found that one of the possible risk factors for sexual problems was being single. This knowledge could facilitate offering information and possible guidance to those who need it the most. Up to two thirds of testicular cancer patients still experience a strong need for information concerning sexuality and one fifth experienced a need for support on this matter, even longer after treatment (42). However, many men find talking about genitally-related health problems difficult (43). Health care workers should pay extra attention to single testicular cancer patients, as they appeared more vulnerable to experiencing sexual problems in the first year after diagnosis.

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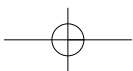
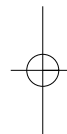
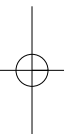
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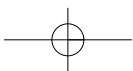
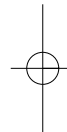
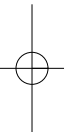
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chapter 8 **general discussion**





In this chapter the overall conclusions that can be drawn from this thesis will be discussed and placed in a broader context. Thereafter some methodological issues of the studies reported will be discussed. The chapter will end with suggestions for future research and clinical implications of the findings.

This thesis addressed the psychosocial and sexual functioning of testicular cancer survivors and their spouses, and possible differences in functioning of survivors according to relationship status. The few earlier studies on functioning of couples after treatment for testicular cancer included a small number of couples and studied functioning on group level. Besides, no studies have investigated possible differences between survivors who were and remained in a relationship, those who were single at time of treatment and remained single, and those who developed a relationship after they completed treatment. The general aims of the thesis were to study:

1. the functioning of spouses of testicular cancer patients and survivors
2. correspondence in functioning between survivors and spouses
3. differences in functioning according to relationship status
4. effect of medical, personal and social variables on functioning

Overall conclusions

Functioning of spouses

In the introduction of this thesis we emphasized the importance of including spouses in studies on functioning after testicular cancer, as spouses may be affected by the cancer experience as well. The studies showed that on the whole, spouses of long term testicular cancer survivors function well, but that some are negatively affected by the experience.

On group level it appeared that spouses experienced good functioning. Spouses experienced a comparable quality of life as the average Dutch woman, and even better physical functioning. Marital satisfaction of spouses was also comparable to that of the average woman. Spouses experienced low to moderate levels of stress response symptoms (e.g. intrusive thoughts about the cancer and treatment, nightmares about the cancer period). Surprisingly, no relationship was found between functioning and time since treatment, suggesting that spouses whose partner's cancer treatment had been completed shortly ago reported comparable functioning to spouses whose partner's treatment had been completed longer ago. On an individual level, half of all spouses experienced clinically elevated levels of stress response symptoms shortly after diagnosis; one year later this percentage had dropped to eleven. This percentage was comparable to that found in spouses of men whose treatment had been completed years ago, of whom fourteen percent still experienced clinical stress response symptoms. The finding that level of stress response symptoms is independent of time since treatment completion, and that prevalence of clinically elevated symptoms is comparable in the short- and in the long-term following treatment suggest that some spouses become and remain distressed. Clinically elevated levels strongly indicate the presence of a

post traumatic stress syndrome (PTSS), a psychiatric diagnosis for which psychological treatment is recommended (1). Although none of the couples in the present study divorced during or following treatment, it did appear that 22% of spouses experienced low marital satisfaction comparable to that of couples referred for counseling, indicating marital problems. Lastly, on group level, spouses of survivors experienced deteriorated sexual satisfaction, as they were less satisfied than women from a reference group.

The findings on the prevalence of clinically elevated stress response symptoms and marital and sexual problems do not necessarily imply that spouses are at risk for an impaired quality of life due to their experience. Spouses reported comparable levels of problems to those found in the general population, at least for PTSS and marital problems. In general, PTSS is found in 7-12 percent of people, and it often follows a diagnosis of cancer or another serious physical illness (2). Besides, the finding that 50% of spouses experiences clinically elevated distress shortly after diagnosis is to be expected as this period is most stressful for both patients and their families (3). The percentage of women burdened with clinically elevated stress response symptoms drops dramatically over the first year from fifty to eleven percent. The level of marital problems in spouses of testicular cancer survivors is also in line with earlier studies on marital problems after cancer that report strains in 10 – 20 percent of marriages (4). The decrease in sexual functioning cannot be ignored in this particular group of spouses of cancer patients and survivors.

All of the findings mentioned above apply to spouses who had a relationship with the survivor when he fell ill (long-term spouses). As testicular cancer strikes at a young age, a relatively large group of patients will not yet have developed a steady relationship at time of diagnosis, and new relationships are likely to be formed after treatment has ended. A previously unstudied group was therefore studied: spouses who developed a relationship with the testicular cancer survivor an average of six years after he completed treatment (new spouses). Findings indicated that functioning of these new spouses was mostly similar to that of long-term spouses: they too experienced better physical functioning and comparable marital satisfaction as long-term spouses. However, some noteworthy differences were found as well. New spouses experienced more problems within the psychological quality of life domains (emotional problems, mental health, and vitality) than both long-term spouses and the average Dutch woman. It is unclear whether this worse psychological functioning was present before onset of the relationship with the survivor, or might result from possible negative consequences of the disease that affect the relationship (such as infertility or remaining health problems of the survivor). New spouses reported some intrusions related to their husband's cancer, although they did not experience the cancer episode themselves. New spouses experienced some intrusive ideas, images and feelings about the cancer event, maybe as a result of discussing the illness period with the survivor and integrating this into their own memory. These intrusions could be a reflection of cancer-related worries in new spouses, maybe they fear a recurrence or negative sequel that impact their life as well.

In sum, many results of this thesis showed how important it is to take spouses of testicular

cancer patients into account, in particular new spouses. A minority may need professional support for remaining clinical stress response symptoms and the deteriorated sexual satisfaction is also a concern in this group. Moreover, new spouses of testicular cancer survivors may be at risk for psychological problems.

Correspondence in functioning

With respect to the second aim of this thesis, results of the studies showed correspondence in survivor and spouse functioning, meaning that functioning in couples is associated. An exception was found shortly after diagnosis however. At that time, if one spouse was experiencing more stress response symptoms, the other experienced less. This is probably the result of a protective mechanism within couples when one party remains strong to support the other. In the longer term however, levels of emotional problems, mental health, stress response symptoms, marital and sexual satisfaction in couples of survivors and spouses was positively related. Meaning that if one spouse functioned better or worse, the other did too. Especially sexual functioning was very strongly related in couples, but mostly the associations found were moderate. This is in line with the results of a recent meta-analysis of distress in couples coping with cancer that showed that distress is moderately associated (5). Another meta analysis on association between caregiver and patient distress showed that the association becomes stronger as time passes, and that in particular distress of male patients and female caregivers were found to be strongly associated (6).

A relevant finding of this thesis was that even though functioning appeared related within couples, spouses sometimes experienced more problems than survivors themselves. In the longer term, spouses more often experienced marital problems than their husbands (22% vs 12%), they experienced more stress response symptoms and more often were found to be clinically distressed. Spouses also expressed their negative emotions more than survivors, although this was found to be no problem in itself. This is probably the result of our entirely female spouse population, as women were found to report more distress than men after a cancer diagnosis, regardless of whether they were the patient or the spouse (5). This thesis showed that correspondence does not necessarily mean equal functioning, and that female spouses are at risk for experiencing more distress than testicular cancer survivors.

Again, findings differed according to onset of the relationship. In couples who developed a relationship after completion of treatment, quality of life and stress response symptoms were not significantly related. Marital satisfaction was weakly related in new couples, but sexual satisfaction was very strongly related. It also appeared that survivors and new spouses experienced similar levels of marital and sexual satisfaction. This indicates that going through the cancer experience together impacts the patients and spouses as a dyad, and that the cancer is a joint experience. When a couple develops a relationship afterwards, functioning is more independent of each other.

Differences in functioning according to relationship status

The introduction of this thesis addressed the advantage of being in a relationship when one is confronted with cancer, as earlier studies showed better physical and psychological functioning in committed cancer patients. Findings of the current studies confirm this advantage in testicular cancer patients as well as in survivors, and show how important it is to take relationship status into account. Overall, survivors with the same partner as at time of diagnosis experienced the best level of functioning, followed by survivors who developed a relationship afterwards, and lastly patients and survivors who were and stayed single. Differences between these groups were found in sexual functioning, depressive symptoms, sexual satisfaction, marital problems, mental health, and self esteem. Differences were found in the first year following diagnosis as well as in the longer term, indicating that being a single testicular cancer patient or survivor is a continuing risk factor for lower well being.

Effect of medical, personal and social variables on functioning

The effect of social variables on functioning has been discussed above. Overall, risk-factors for impaired functioning appear to be a worse functioning of one partner (as functioning in couples is related), being a single testicular cancer patient or survivor, and being a new spouse of a testicular cancer survivor. The expression of negative emotions was taken into account as a personal variable, and it did not appear related to functioning in either survivors or spouses. Objective disease related characteristics (time since treatment, type of treatment and occurrence of a second cancer event) were found to be very weakly related to functioning of testicular cancer survivors in earlier studies (7). This thesis showed the following relationships. Both survivors and spouses who were confronted with a second cancer event experienced less sexual satisfaction than those who were not. Additionally, spouses of men who were treated with more intensive treatment experienced more stress response symptoms than spouses of men who underwent surgery only. More advanced disease results in having to undergo more intensive treatment, and a second cancer diagnosis may damage trust in achieving full recovery after the first cancer experience. It may be that a second cancer event as well as advanced disease result in insecurity, explaining the lower sexual satisfaction and the higher stress response symptoms.

Functioning of testicular cancer patients and survivors

The functioning of patients and survivors was not the main aim of this thesis, it was studied in relation to that of the spouse, and to his own relationship status. However, the results found on functioning of survivors and patients themselves are worthwhile mentioning. Testicular cancer survivors reported good functioning, with low levels of stress response symptoms and marital satisfaction comparable to that of men not confronted with cancer. A year after diagnosis patients even reported better physical functioning than men from a reference group. On the other hand, survivors had decreased sexual satisfaction, and 25% of survivors

with a new spouse experienced marital problems. Shortly after diagnosis, a quarter of patients experienced clinically elevated stress response symptoms; one year later this percentage had dropped to 16. Shortly after diagnosis a quarter of patients also suffered from depression, one year later 16% reported depression. This last finding is in line with prevalence of depression in cancer patients of whom 13% suffer from depression in the first two years after diagnosis (8). In testicular cancer survivors 10% suffer from depression in the long-term, which is comparable to the percentage found in the general population (9). The current study showed that recovery for some patients was probably not finished one year after diagnosis, and that these survivors may benefit from a professional psychological intervention.

Methodological considerations

The separate chapters of this thesis all include a section in which the strengths and weaknesses of the designs and methods used are described, and thus these reflections will not be repeated here. However, there are some considerations about the entire study. Besides the positive aspects of the current thesis (inclusion of a large group of survivors as well as spouses, a large range in time since diagnosis, a combination of cross-sectional and longitudinal studies, a uniform survivor and spouse population, and the use of validated questionnaires), there are also some limitations. Firstly, even though most questionnaire manuals provided (norm-)data on reference groups, the current thesis lacked control groups for both survivors and spouses. A comparison group for the survivors was included in the study on emotional expression, but as was mentioned in the discussion section of that chapter, it appeared that these comparisons may be less suitable due to a possibly biased selection. Secondly, the groups of couples who developed a relationship after completion of treatment ($n=40$) and single patients and survivors ($n=40$) were limited in sample size. The large difference in sample size between the group of new couples and that of long term couples might have hindered finding more or stronger significant differences in functioning. Thirdly, it might be that there is a response bias towards good functioning couples. Couples that separated or those troubled by marital problems may be less willing to participate, as refusal to participate in a study has been found related to poorer mood (10). A second response bias might be underlying the studies in this thesis. As mentioned in the introduction, a number of previous studies on testicular cancer patients and survivors has been performed at the University Medical Centre in Groningen. Some survivors may have declined to participate, because they had already participated in earlier studies initiated by the UMCG testicular cancer research group. Finally, certain issues were not addressed that might have been important in this particular survivor group. For instance, no information was gained on fertility distress or the wish to have (more) children. Besides, homosexual couples (3 participated) were not included in the study to maintain a uniform spouse population. It might well be that dyadic functioning is different in homosexuals.

Model of research and future research

The model underlying this thesis (see Figure 1 in the introduction of the thesis) was based on the research model for psycho-oncology described by Holland et al (11). This model was expanded by including the spouses and studying correspondence within couples. This adapted model proved to be useful for the aims of the current thesis and made it possible to build on previous studies on functioning of couples after cancer. However, with this model it was not possible to gain insight into the adaptation process that leads to current functioning and how distress levels of survivor and spouse affect each other. Nor is it useful to provide information on which dyads may be functioning better than others (comparison of dyads). To study moderating variables (e.g. illness characteristics, personality characteristics and coping styles) for distress in dyads might be more suitable (5;12-14). The longitudinal study described in chapter 5 was limited in sample size, mainly due to the rare incidence of testicular cancer. A longitudinal study is needed with more couples and a longer time period of study, for example during the first 5 years after diagnosis to examine risk factors for adaptation problems in couples and at which time point possible interventions might be most beneficial. Besides, including all new testicular cancer patients in a longitudinal study will provide further information on the functioning of single patients and those who start a new relationship after treatment.

In order to gain more insight into functioning of new spouses, a larger study sample is needed. The decreased psychological functioning in new spouses found in this study needs further exploration. This study must include personality traits and prior life events as well, to tackle the question whether lower functioning existed before onset of the relationship or may be a result of having a relationship with a cancer survivor.

After a long international tradition of studying functioning in testicular cancer patients, the area of research could be expanded to relationship aspects following cancer in other groups, such as childhood cancer survivors. Impact on the relationship, finding a partner and fertility are important issues in this and other groups of cancer survivors (15). The use of specific questionnaires for long term survivors addressing their concerns, self evaluation, positive and negative consequences, social life interferences, relationships and meaning of their experience with cancer is necessary (16;17).

Clinical implications

Patients and spouses seem to adjust well to their experience with testicular cancer. However, depressed patients and a small group of spouses may benefit from additional professional care and single patients from more information and guidance. Testicular cancer patients who are depressed might benefit from a combination of psychosocial and pharmacologic interventions (18). In general, PTSS is found to uniquely impact on well-being of those who suffer from it and it is related to suicide attempts (2). The 14% of spouses of long term testicular cancer survivors having clinical distress should not be left untreated. Spouses can benefit from a cognitive-behavior group intervention that proved to be very useful in reducing dis-

stress in relatives of cancer patients (19). From such an intervention spouses can learn to discover their own negative thinking patterns, learn to challenge their beliefs and restructure thoughts and behavior into more adaptive patterns. Especially learning to accept, have realistic expectations about recovery of their husband, and giving meaning to their experience with cancer can reduce distress and improve satisfaction with life (20;21).

Testicular cancer survivors have reported to be in need of more information on the side effects of their treatment and long-term functioning (22;23). When cancer patients see their expectations on recovery fulfilled, they experience a better quality of life and less distress (21). Providing additional information might be especially beneficial for single testicular cancer patients, as they appear to be a vulnerable group when it comes to self-esteem, mental health and sexuality. Unrealistic beliefs may be underlying this vulnerability, and realistic information on their health and future functioning may eliminate these. Provide room for them to discuss when to tell a possible spouse about their cancer experience and their beliefs about their own sexuality.

Couples should be provided with information on sexual functioning as well. However, open communication about possible changes in sexuality due to cancer and its treatment, seems not to be easy for both health professionals and patients (24). It has been found that patients seek support and practical strategies about their sexual and intimate life, whereas health professionals focus on physical functioning (25). In the Netherlands, the general practitioner might be a key figure in addressing the needs of the couple after treatment for testicular cancer, as his care is aimed at the entire family and not only the patient or survivor.

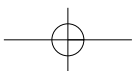
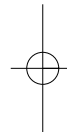
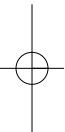
Routinely offering psychological therapy is not the best practice in this patient group however. An earlier study showed that testicular cancer patients who entered a psychological intervention were more distressed one year after treatment than patients who received standard care (26). Besides, evidence for the effectiveness of psychosocial interventions to reduce distress in the typical cancer patient is rather weak (27). Interventions for the subgroup of patients who are clinically distressed are more useful and promising however.

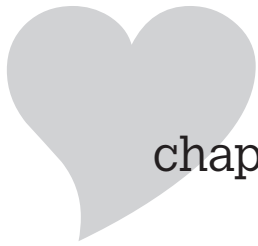
A useful tool to facilitate communication between doctors and patients, and to detect clinically distressed patients is a short screening instrument called the distress thermometer (DT) (3). Patients fill in this ultra short screening list themselves and indicate their level of distress as well as the problems they experience in the physical domain (including sexuality) and in practical, social, emotional and spiritual domains. High scores on the distress thermometer give an indication to refer respondents to professional supportive care services. Structural screening for distress during treatment but also in the years of follow up can take away the stigma associated with emotional, social and sexual needs, and facilitates giving periodical attention to psychosocial functioning of patients (28;29). Screening of distress in family members of cancer patients with the use of the thermometer appeared efficient and reliable as well (30). At best both testicular cancer patients and spouses are screened for distress, as their functioning is related. Providing the best care for testicular cancer patients therefore includes their spouses to facilitate optimal recovery.

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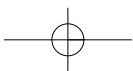
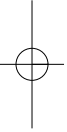
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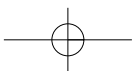
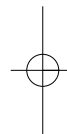
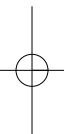
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chapter 9 **summary**





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.

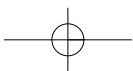
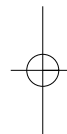
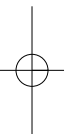
Being single appears to be a risk factor for psychological distress, and reduced self-esteem or body image problems after cancer. Being single might also result in the receipt of less social support, which can possibly affect mental health in a negative way. However, almost no research has been performed 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.

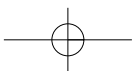
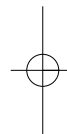
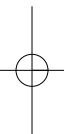
Chapter 7 describes a study aimed to prospectively and longitudinally investigate sexual functioning during the first year following surgery. Again, the focus lies on possible differences in sexual functioning between single testicular cancer survivors (39% of sample) and those with a partner, but also 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.



chapter 10 **samenvatting**





Zaadbalkanker wordt voornamelijk bij jonge mannen vastgesteld en is, zelfs wanneer er uitzaaiingen zijn, goed te genezen: bijna 90% van de patiënten overleeft de ziekte. De kwaliteit van leven van de patiënt kan beïnvloed worden door de ervaring met kanker. Kwaliteit van leven is een multi-dimensioneel concept dat weergeeft hoe iemand zijn lichamelijke, psychische en sociale functioneren ervaart. De ervaring met de ziekte en behandeling heeft echter niet alleen gevolgen voor de patiënt zelf, maar ook voor de partner. Dit blijkt uit een beperkt aantal onderzoeken naar de kwaliteit van leven na zaadbalkanker dat zich ook op het functioneren van de partner richtte. Deze onderzoeken omvatten echter kleine aantallen deelnemers, en onderzochten het functioneren op groepsniveau en gaven dus geen inzicht in functioneren binnen het paar. Daarnaast werd in onderzoek weinig aandacht besteed aan vrijgezelle mannen die zaadbalkanker hebben (gehad) en helemaal geen aandacht aan mannen die een vaste relatie kregen nadat zij waren behandeld voor zaadbalkanker. Het doel van dit proefschrift was dan ook om inzicht te krijgen in het functioneren van partners van mannen die genezen zijn van zaadbalkanker en te onderzoeken of er overeenkomsten zijn in het functioneren van mannen en hun partners (hoofdstukken 2, 3, 4 en 5). Daarnaast werd onderzocht of er verschillen in functioneren zijn tussen vrijgezelle mannen die zaadbalkanker hebben gehad, mannen die dezelfde partner hebben als bij diagnose en mannen die na hun behandeling een vaste partner hebben gekregen (hoofdstukken 6 en 7). Mannen die in de afgelopen 25 jaar zijn behandeld en hun partners hebben meegedaan aan dit onderzoek, inclusief een groep patiënten tijdens het eerste jaar na diagnose.

De diagnose kanker is soms zo emotioneel ingrijpend dat het kan leiden tot stress respons symptomen, die zelfs maanden tot jaren na afronding van de behandeling aanhouden. Deze symptomen bestaan uit terugkerende en onaangename gedachten en herinneringen aan de ziekteperiode en uit het proberen om situaties die deze herinneringen oproepen te vermijden. *Hoofdstuk 2* beschrijft een onderzoek naar het voorkomen van stress respons symptomen en naar de kwaliteit van leven van partners van mannen die genezen zijn van zaadbalkanker en op overeenkomsten hiervan binnen de paren. Deelnemers aan de studie waren 259 paren van genezen mannen die tussen 0,5 en 25 jaar geleden geconfronteerd werden met zaadbalkanker en hun (vrouwelijke) partners. Een niet eerder onderzochte groep partners deed eveneens mee: partners die een relatie kregen met de man nadat zijn behandeling was afgerond ($n=40$). Zowel kwaliteit van leven als stress respons symptomen van partners bleken niet gerelateerd aan hoe lang de behandeling afgerond was. Partners waardeerden hun lichamelijk functioneren als beter dan een referentiegroep van Nederlandse vrouwen. Het bleek dat het functioneren van partners die al een relatie hadden met de man voor diagnose en behandeling (oorspronkelijke partners) verschilde van partners die pas na afronding van de behandeling een relatie kregen (nieuwe partners). Nieuwe partners ervaarden meer problemen op het gebied van mentale kwaliteit van leven dan zowel oorspronkelijke partners als een referentiegroep van Nederlandse vrouwen. Ook al hebben nieuwe partners de

periode van diagnose en behandeling niet meegemaakt, toch rapporteerden zij soms gedachten en herinneringen hierover te ervaren. Oorspronkelijke partners rapporteerden als groep een laag niveau van stress respons symptomen, alhoewel 14% een klinisch verhoogd niveau van symptomen meldde waarvoor professionele ondersteuning nodig zou kunnen zijn. Verder bleek dat partners van mannen die een combinatie van behandelingen hadden ondergaan meer stress respons symptomen ervaarden dan partners van mannen die alleen geopereerd werden voor zaadbalkanker. Het bleek dat de mate van stress respons symptomen gerelateerd was binnen paren (als één partner meer symptomen ervaart, geldt dit ook voor de andere), maar partners rapporteerden meer symptomen dan de mannen zelf. Deze studie laat zien dat partners die al een relatie hadden met de man ten tijde van zijn diagnose en behandeling een goede kwaliteit van leven ervaren en een laag niveau van stress respons symptomen. Functioneren van nieuwe partners lijkt echter minder goed te zijn op diverse domeinen van kwaliteit van leven, vooral de psychologische aspecten. Onduidelijk is of partners al een slechter functioneren ervaarden voordat zij een relatie kregen of dat dit komt door eventuele negatieve gevolgen van de zaadbalkanker binnen de relatie. Verder onderzoek naar het opbouwen van een relatie na een kankerdiagnose kan meer inzicht geven in deze resultaten.

De studie die beschreven wordt in *Hoofdstuk 3* richtte zich op de tevredenheid met de relatie op emotioneel en seksueel gebied van mannen die genezen zijn van zaadbalkanker en hun partners. Eerdere onderzoeken naar seksualiteit en relatietevredenheid na zaadbalkanker waren voornamelijk gericht op de ervaringen van de man en niet op tevredenheid van de partner noch op overeenkomsten binnen het paar. In het beschreven onderzoek werd de tevredenheid van paren die al een relatie hadden voor diagnose (oorspronkelijke paren, n=219) vergeleken met die van paren die een relatie kregen na afronding van de behandeling (nieuwe paren, n=40). Daarnaast werd gekeken naar mogelijke verschillen in tevredenheid tussen paren die geconfronteerd waren met zaadbalkanker en een referentiegroep, naar verschillen tussen mannen en hun partners en of ziekte en naar de relatie tussen behandelingsvariabelen en tevredenheid. Paren konden aangeven of ze vonden dat hun relatie beïnvloed werd door hun ervaring met zaadbalkanker. Resultaten lieten zien dat genezen mannen in een nieuwe relatie minder seksuele tevredenheid ervaarden dan genezen mannen die dezelfde partner hadden als voor diagnose, maar een gelijke relatietevredenheid. Voor partners werden er geen verschillen gevonden. Na vergelijking met referentiegroepen van mannen en vrouwen bleek dat paren die geconfronteerd waren met zaadbalkanker even tevreden waren over hun relatie, maar alle genezen mannen en de oorspronkelijke partners waren minder tevreden met hun seksuele relatie. Afgaande op de kleine *effect sizes* van de verschillen lijkt een interventie voor seksueel functioneren echter niet nodig voor al deze paren. Wat betreft de ziekte- en behandelingsgerelateerde variabelen bleek alleen dat als de genezen man een tweede keer geconfronteerd werd met kanker (andere diagnose kanker of tweede zaadbalkanker), zowel hij als zijn partner minder seksuele tevredenheid ervaarden

dan paren die niet geconfronteerd werden met een tweede kankerdiagnose. Relatietevredenheid tussen partners in oorspronkelijke paren was matig gerelateerd en seksuele tevredenheid heel sterk gerelateerd (als één partner meer of minder tevreden was, gold dat ook voor de andere). In overeenkomst met onderzoeken in de algemene populatie, bleek binnen de groep van oorspronkelijke paren dat de vrouwelijke partners minder tevreden over hun relatie waren dan de genezen mannen. Partners ervoeren ook vaker (22%) relatieproblemen waarvoor een interventie nodig zou zijn dan de genezen mannen (12%). Binnen de groep van nieuwe paren was relatietevredenheid zwak, maar seksuele tevredenheid zeer sterk gerelateerd. Gemiddeld waren genezen mannen en partners van nieuwe paren even tevreden over hun relatie, maar binnen deze groep ervoeren de mannen (25%) juist vaker relatieproblemen dan de partners (18%). Bijna de helft van de oorspronkelijke paren gaf aan geen veranderingen te ervaren in de relatie door de confrontatie met zaadbalkanker, meer dan 40% gaf zelfs aan dat de relatie verbeterd was en een minderheid gaf aan dat de relatie verslechterd was. De meerderheid van mannen (57%) en partners (54%) die een relatie kregen na afronden van de behandeling gaf aan dat de confrontatie met zaadbalkanker een kleine tot geen rol speelde in de relatie. Paren die geconfronteerd zijn met een diagnose zaadbalkanker zouden baat kunnen hebben bij informatie over de gevolgen hiervan op hun seksuele relatie. Vooral genezen mannen die na diagnose een relatie krijgen zijn minder tevreden.

In *hoofdstuk 4* wordt een studie beschreven over de expressie van negatieve emoties zoals angst, woede en depressie. Eerder onderzoek toonde aan dat emotionele expressie gerelateerd is aan verschillende psychische en zelfs fysieke voordelen na een kankerdiagnose. De huidige studie richt zich op de emotionele expressie van mannen genezen van zaadbalkanker en hun partners en op de relatie tussen emotionele expressie en functioneren. Gekeken werd naar verschillen in expressie tussen genezen mannen en een controlegroep van mannen die geen kanker hebben gehad, en tussen genezen mannen en hun partners. Daarnaast werd onderzocht of er een relatie bestaat tussen expressie en ziekte- en behandelingsvariabelen en of de mate van expressie van genezen mannen en hun partners gerelateerd is aan zowel hun eigen functioneren als dat van de ander. Stress respons symptomen, relatietevredenheid en mentale gezondheid werden meegenomen als parameters van functioneren. Deelnemers aan de studie waren 219 paren van mannen genezen van zaadbalkanker en hun partners die al een relatie hadden voor de diagnose. Mannen die genezen zijn van zaadbalkanker uitten hun negatieve emoties minder vaak dan hun partners en veel minder vaak dan mannen uit de controlegroep. Dit laatste verschil bleek klinisch relevant, wat betekent dat het merkbaar is in het dagelijks leven. Het lijkt erop dat de ervaring met kanker geleid heeft tot een vermindering in het uiten van negatieve emoties. Opvallend resultaat was dat genezen mannen op een extra vraag aangaven dat zij sinds hun diagnose zaadbalkanker in het algemeen meer emoties uiten. Het zou kunnen zijn dat mannen genezen van zaadbalkanker positieve emo-

ties zoals geluk, liefde en plezier vaker uiten, maar de negatieve emoties minder zijn gaan uiten. Een derde van de partners gaf aan dat zij hun emoties meer uiten sinds de diagnose van hun man, de helft gaf aan geen veranderingen in expressie te ervaren. Losstaande ziekte- en behandelingsvariabelen bleken niet gerelateerd te zijn aan mate van emotionele expressie, hetgeen erop kan duiden dat de kankerervaring als geheel belangrijker is in het verklaren van veranderingen in expressie. Daarnaast bleek dat de mate van expressie van zowel de genezen mannen als van de partners niet gerelateerd was aan hun eigen functioneren noch aan dat van de ander. De expressie van negatieve emoties van mannen, genezen van zaadbalkanker, bleek verminderd sinds de diagnose, maar dit heeft geen relatie met het functioneren van het paar of hun relatietevredenheid. Een interventie gericht op het faciliteren van expressie lijkt dan ook niet nodig.

Ter aanvulling op de retrospectieve onderzoeken beschreven in hoofdstukken 2, 3 en 4, werd een prospectieve longitudinale studie uitgevoerd die wordt beschreven in *Hoofdstuk 5*. De studie was gericht op het beloop van stress respons symptomen en kwaliteit van leven van zaadbalkankerpatiënten en hun partners in het eerste jaar na de diagnose en behandeling van zaadbalkanker. Negentien paren rapporteerden over hun functioneren op drie meetmomenten: vlak voor de start van chemotherapie (T1), na afronding van de chemotherapie (T2, drie maanden later), en één jaar later (T3). Naast het individuele beloop van functioneren werd gekeken naar overeenkomsten in functioneren binnen het paar, naar de voorspellende waarde van functioneren op T1 op later functioneren en het verschil in functioneren tussen paren en referentiegroepen van mannen en vrouwen. Voor de start van chemotherapie rapporteerden 26% van de patiënten en 50% van de partners klinisch verhoogde stress respons symptomen, na afronding van de chemotherapie waren stress respons symptomen bij de paren verminderd. Een jaar na diagnose rapporteerden patiënten weer een lichte stijging in symptomen (16% klinisch verhoogd niveau), maar voor partners was het niveau verder gedaald (10% klinisch verhoogd niveau). Wat betreft kwaliteit van leven bleek dat patiënten het slechtste fysiek en sociaal functioneren ervaren na afronden van de chemotherapie in vergelijking met T1 en T3. Verrassend was dat patiënten op T1 en T3 een beter lichamen functioneren rapporteerden dan de referentiegroep. Partners rapporteerden alleen veranderingen in sociaal functioneren, dat verbeterde gedurende het jaar. Net als patiënten ervaren zij op T1 en T3 een beter lichamen functioneren dan de referentiegroep. In vergelijking met de referentiegroep ervaren zowel patiënten als partners voor de start van chemotherapie een slechter sociaal functioneren dan de referentiegroepen. Een jaar na diagnose was er geen verschil meer in sociaal functioneren tussen paren en de referentiegroepen. Het beloop van het functioneren was dus verschillend voor patiënten en voor partners, en correlaties tussen beider functioneren waren matig tot zwak. Stress respons symptomen bij patiënten en bij partners waren negatief aan elkaar gerelateerd op T1, hetgeen betekent dat als de ene partner meer symptomen rapporteerde, de andere aangaf minder symptomen

te ervaren. Patiënten die voor de start van chemotherapie veel stress respons symptomen rapporteerden, deden dit ook na afronden van de chemotherapie en één jaar later; dit patroon werd niet gevonden voor kwaliteit van leven. De mate van stress respons symptomen van partners voor de start van chemotherapie was niet voorspellend voor hun latere mate van symptomen; hun kwaliteit van leven op T1 was wel voorspellend voor later functioneren. Het lijkt erop dat de negatieve invloed van uitgezaaide zaadbalkanker op het functioneren van patiënten en partners van tijdelijke aard is. Een jaar na diagnose zou een minderheid baat kunnen hebben bij ondersteuning voor klinisch verhoogde stress respons symptomen.

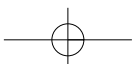
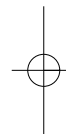
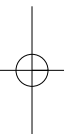
Het niet hebben van een vaste, intieme relatie lijkt een risicofactor te zijn voor psychologische stress, verminderd zelfvertrouwen en problemen met het uiterlijk na een kankerdiagnose. Daarnaast is vrijgezel zijn een risicofactor voor verminderde sociale steun, dat kan leiden tot een verslechterde mentale gezondheid. Er is echter zeer weinig onderzoek gedaan naar verschillen in functioneren na een kankerdiagnose gebaseerd op burgerlijke staat. Het doel van de studie in *Hoofdstuk 6* was dan ook om te onderzoeken of mannen die genezen zijn van zaadbalkanker en geen vaste intieme relatie hebben (vrijgezel, n=40) verschillen in functioneren van genezen mannen die dezelfde partner hebben als voor diagnose (oorspronkelijke relatie, n=49) en genezen mannen die na afronden van behandeling een vaste relatie kregen (nieuwe relatie, n=40). Gekeken werd naar verschillen in de hoeveelheid ontvangen sociale steun, de tevredenheid met ontvangen steun, het gevoel van eigenwaarde en de mentale gezondheid. Daarnaast werd onderzocht of sociale steun en gevoel van eigenwaarde bijdragen aan mentale gezondheid in deze drie groepen. De drie groepen rapporteerden allen een gelijke mate van ontvangen sociale steun, de tevredenheid met deze steun verschilde echter wel. Genezen mannen met een oorspronkelijke relatie waren het meest tevreden en vrijgezelle mannen het minst. Ook al gaven vrijgezelle mannen aan evenveel sociale steun te ontvangen als de andere twee groepen, toch waren zij hier minder tevreden mee. Het lijkt erop dat aan hun behoefte aan sociale steun niet voldaan werd. De steun die mannen van hun partner krijgen, voldoet waarschijnlijk meer aan de behoefte dan steun van anderen uit de omgeving. Gevoel van eigenwaarde en mentale gezondheid verschilde ook tussen de drie groepen. Mannen met een oorspronkelijke partner rapporteerden het grootste gevoel van eigenwaarde en de hoogste mentale gezondheid. Genezen mannen met een nieuwe relatie rapporteerden een groter gevoel van eigenwaarde dan vrijgezelle mannen, maar een gelijke mentale gezondheid. Mannen met een nieuwe relatie en vrijgezelle mannen hadden een slechtere mentale gezondheid dan een referentiegroep. Het verschil in gevoel van eigenwaarde tussen mannen met een oorspronkelijke relatie en vrijgezelle mannen was het grootst en ook klinisch relevant. Zowel mannen met een nieuwe relatie als vrijgezelle mannen lijken problemen te ervaren die hun mentale gezondheid vermindert. Onderliggende mechanismen die deze verschillen in mentale gezondheid verklaren moeten verder onder-

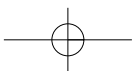
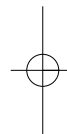
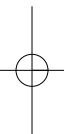
zocht worden. Specialisten en verpleegkundigen moeten zich bewust zijn van de kwetsbaarheid van vrijgezelle patiënten, omdat deze een risico lopen op een verminderde mentale gezondheid en een laag gevoel van eigenwaarde.

In *Hoofdstuk 7* wordt een prospectieve longitudinale studie beschreven naar het beloop van seksueel functioneren en van depressieve symptomen in het eerste jaar na diagnose. In deze studie lag de nadruk op zowel het beloop van functioneren als op mogelijke verschillen in functioneren tussen zaadbalkankerpatiënten met een vaste partner (n=57) en vrijgezelle patiënten (n=36). Daarnaast werd de relatie tussen seksueel functioneren en ziektegerelateerde variabelen en depressieve symptomen onderzocht. Patiënten rapporteerden over hun functioneren op 3 meetmomenten: vlak na operatie (T1), drie maanden later (T2), en één jaar later (T3). Patiënten uit twee grote verwijscentra in Nederland (Universitair Medisch Centrum Groningen) en in de Verenigde Staten (MD Anderson Cancer Centre in Houston, Texas) deden mee aan deze studie. Zaadbalkankerpatiënten rapporteerden veranderingen in alle aspecten van seksueel functioneren behalve in verlangen, dat onveranderd bleef. Voor het functioneren op het gebied van orgasme, algemene tevredenheid en algeheel seksueel functioneren rapporteerden patiënten het slechtste functioneren drie maanden na operatie, terwijl zij een jaar later een verbetering rapporteerden tot boven het beginniveau van T1. Functioneren op het gebied van erectie en tevredenheid met geslachtsgemeenschap bleef gelijk op T1 en T2 maar was een jaar na operatie verbeterd. Type behandeling (75% van de patiënten onderging ook chemotherapie) was niet gerelateerd aan het seksueel functioneren. Depressie kwam het meest voor vlak na operatie: 26% van de patiënten rapporteerde zoveel depressieve symptomen dat zij baat zouden hebben bij professionele ondersteuning. Eén jaar later was dit percentage gedaald naar 16%. Vlak na operatie waren depressieve symptomen zwak tot matig gerelateerd aan seksueel functioneren. Drie maanden en één jaar later was er alleen een matige relatie met algeheel seksueel functioneren. Depressieve symptomen op T1 hadden geen voorspellende waarde voor de kwaliteit van later seksueel functioneren. Er werden wel verschillen gevonden in seksueel functioneren tussen de patiëntgroep met een vaste relatie en de vrijgezelle groep. Vrijgezelle patiënten rapporteerden op alle meetmomenten slechter seksueel functioneren dan patiënten met een vaste relatie, maar de twee groepen verschilden niet in seksueel verlangen. Eén jaar na de operatie rapporteerden vrijgezelle patiënten ook op drie domeinen een slechter seksueel functioneren dan een normgroep van mannen, terwijl patiënten met een vaste relatie meer tevredenheid met geslachtsgemeenschap rapporteerden dan de normgroep. De gevonden verschillen tussen vrijgezelle patiënten en patiënten met een vaste relatie waren statistisch zeer significant, maar *effect sizes* gaven een indicatie dat de verschillen waarschijnlijk klinisch niet erg relevant zijn. De gevonden verschillen tussen vrijgezelle patiënten en de normgroep bleken echter op de grens van klinisch relevant te zijn, wat aangeeft dat een interventie hiervoor nuttig zou kunnen zijn. Vrijgezelle patiënten ervaren wellicht meer onzekerheden op het gebied van seksueel functioneren en zouden gebaat zijn bij goede informatie en voorlichting.



Tot slot worden in *Hoofdstuk 8* de belangrijkste bevindingen van het onderzoek besproken. Daarnaast worden een aantal methodologische kwesties besproken, suggesties voor vervolgonderzoek gedaan en besproken wat de resultaten kunnen betekenen voor de praktijk.





Dankwoord

Als eerste wil ik alle deelnemers aan dit onderzoek bedanken. De patiënten en hun partners hebben veel tijd en moeite genomen om onze talloze vragen te beantwoorden, zowel op papier als tijdens interviews. Individuele reacties zijn niet terug te vinden in dit proefschrift, maar zijn van grote waarde geweest voor het begrijpen van de resultaten die wel beschreven zijn.

Dr. J.E.H.M. Hoekstra-Weebers, beste Josette. Zonder jouw vele investeringen als co-promotor en dagelijks begeleider had ik dit proefschrift niet kunnen schrijven. Met veel enthousiasme over successen, eindeloos geduld bij het corrigeren van artikelen, aanmoediging en hier en daar een onverbidelijke directieve vinger heb je me begeleid naar de voltooiing van dit proefschrift. Ik zal altijd met veel plezier terugdenken aan de congresbezoeken, onze discussies, de ruimte die je maakte voor privégesprekken en je humor. Bedankt!

Het blijft balanceren tussen twee aparte werelden als je als psycholoog promoveert in de medische wetenschappen. Ik had geen betere leraren kunnen bedenken dan mijn twee promotoren.

Prof. dr. D.Th. Sleijfer, beste Dirk. Bedankt dat je mijn eerste promotor wilde zijn, ook al zag ik dat in het begin met angst en beven tegemoet. Met razend tempo, pijnlijk eerlijk commentaar en een adelaarsoog voor inconsequenties heb je dit traject begeleid. Gelukkig ben je naast nogal streng ook sympathiek en hartelijk. Jij hebt me direct en indirect veel geleerd over de dagelijkse medische praktijk en 'hoe dokters denken'. Daarnaast heb je me vooruitgeholpen door je nuchterheid en resultaatgerichtheid: 'dit moet gewoon af!' Heel erg bedankt.

Prof. dr. H.J. Hoekstra, beste Harald. Mijn kennismaking met jou was typerend voor de samenwerking in de jaren erna. In een prettig, informeel maar wel kritisch keurend sollicitatiegesprek legde je de basis. Ondanks je drukke programma was je ontspannen, geïnteresseerd in een discussie over onderzoek en heel toegankelijk. Je maakte altijd tijd voor vragen en overleg. Tussen de bedrijven door kwam je met wapperende witte jas langslopen bij de kamers van de onderzoekers, met vragen, suggesties en nieuwe ideeën voor een artikel. Of ik moest bijna uitglijdend in de hal je bij zien te houden om een gecorrigeerd stuk op te halen. Aan jou heb ik niet alleen drie leuke jaren in het UMCG en een proefschrift te danken, maar ook het ontmoeten van mijn echtgenoot. Heel erg bedankt.

Het leven is wat je overkomt terwijl je druk bezig bent andere plannen te maken. Dat was zeker zo voor mij in de jaren van werken aan dit proefschrift. Dirk, Harald en Josette: bedankt voor jullie geduld.

Prof. dr. E.C. Klip, beste Ed. Bedankt voor je begeleiding bij dit project, het was erg prettig om een psychosociale bondgenoot te hebben bij onze projectoverleggen. Als nuchtere professor met emeritaat kon je van afstand soms het beste de juiste conclusie trekken en vooral bij mij even de stress reduceren. Bedankt ook voor je gastvrijheid buiten het ziekenhuis.

With the intervention of the internet, it has become possible to work together without ever meeting. I am lucky to have done so with Professor E.R. Gritz and Dr. D.J. Vidrine from The University of Texas M.D. Anderson Cancer Center. Ellen and Damon, thank you for collaborating on the longitudinal studies. It would be nice to meet in person someday!

Imi Veldman, als onderzoeksassistent heb jij het fundament onder dit onderzoek gelegd. In de vorm van dataverzameling, interviews, maar ook kopjes Senseo zorgde je voor de nodige ingrediënten voor promoveren. Onze gedeelde paranimfentijd was erg leuk, dankjewel voor alles.

Dr. J. Fleeer, lieve Joke. Als eerste en meest belangrijke: ik ben blij dat je er bent. Daarnaast ben ik dankbaar voor het feit dat je mij zag zitten als collega, je plezier in het leven, dat je mijn bewonderenswaardige voorloper bent, dat je al je inspanningen voor dit onderzoek ruimhartig met mij gedeeld hebt, dat je mijn paranimf bent en vooral: dat we elkaar nu vriendinnen kunnen noemen.

Prof. dr. T.P.B.M. Suurmeijer, Prof. dr. H.B.M. van de Wiel en Prof. dr. W.C.M. Weijmar Schultz: hartelijk bedankt voor het beoordelen van dit proefschrift.

In het UMCG heb ik veel geleerd van, maar bovenal veel lol gehad met Martijn Lutke Holzik, Gea Huizinga, Annemieke Visser, Ellen van Weert (wat was het leuk om je paranimf te mogen zijn!), Wendel Vonkeman, Mattijs de Vries, Tom Pereboom, Brunhild Eijsenga, Anton Breeuwsma, Stacey Gazendam-Donofrio en Hildo Ananias.

Mijn vader, Harry Tuinman, is mijn tweede paranimf. Papa, ik ben heel trots dat je deze dag naast me wilt staan, zoals je bij alle belangrijke momenten in mijn leven er stond.

Thomas, je bent en biedt alles wat ik mij gewenst heb: een echte partner, iemand die door zijn eigen ambitie mij stimuleert om het beter te doen, mij vertrouwen geeft en natuurlijk net zo veel lol om flauwe grappen heeft als ik. Jij en Famke zijn mijn blijdschap. Jullie zijn onlosmakelijk verbonden met het werken aan dit proefschrift en gelukkig ook met mij. Wat heb ik toch een mazzel.