

Quality of life and stress response symptoms in long-term and recent spouses of testicular cancer survivors [☆]

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Abstract

The aim of this study was to gain insight into the quality of life (QoL) and stress response of female spouses of men cured of testicular cancer in the long-term. Time since treatment completion varied from 0.5 to 23.8 years. Two hundred and fifty nine testicular cancer survivors and their spouses completed the Dutch version of the MOS Short Form (SF)-36 and the Impact of Event Scale. QoL data from a reference group of women were used for comparison. Spouses who had relationship with the testicular cancer survivor before the diagnosis (spouses during testicular cancer) had better functioning scores than the reference group, especially with respect to the physical QoL domains. Spouses who had started a relationship after treatment (spouses after testicular cancer) experienced more problems with psychological QoL domains than spouses during testicular cancer and than the reference group. The stress response of spouses during testicular cancer was related to that of the testicular cancer survivors and to the extent of treatment they had received. Although stress response levels were low, spouses during testicular cancer reported more stress response than the testicular cancer survivors. Time since completion of treatment did not affect QoL or stress response. This study showed that spouses during testicular cancer had a good QoL and little stress response. Functioning of spouses after testicular cancer was poorer with respect to various QoL domains, particularly the psychological measures.

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1. Introduction

Cancer is most common in elderly people. In men, 75% who develop cancer are 60 years of age or older [1]. In contrast, testicular cancer mainly affects young men aged 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 of 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 psycho-

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logical 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 any 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 and Gritz and colleagues reported on the same group of testicular cancer survivors and their spouses. Hannah and colleagues studied marital and sexual functioning, whereas Gritz and colleagues 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 testicular cancer survivor and that of his spouse. These four studies that aimed specifically at testicular cancer patients and their spouses had small study populations ($n = 10\text{--}34$).

The present retrospective study was conducted to gain greater insight into the global functioning of spouses of testicular cancer 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 the 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 testicular cancer survivor after the completion of treatment? (3) Do QoL and stress response correspond in the testicular cancer survivor 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)?

2. Patients and methods

2.1. 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 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 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.

2.2. 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 patients 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.

2.3. 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. Employment 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] and university [7]. Information was also obtained from the testicular cancer survivors on their disease and treatment

aspects: date of completion of treatment, type of treatment and the occurrence of tumour relapse or a second primary malignancy. The 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 tumour mass (RRRTM) or orchiectomy and radiotherapy.

QoL 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 two 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 (α ranged from 0.75 to 0.92), while for testicular cancer survivors it was moderate to good (α ranged from 0.67 to 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 testicular cancer 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 ($\alpha = 0.85$).

2.4. 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 the spouses and testicular cancer survivors. Separate anal-

yses 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 with 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 testicular cancer 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'. Furthermore, the testicular cancer survivors were divided into five groups according to the type of treatment received: orchiectomy alone [1], orchiectomy + RPLND [2], orchiectomy + chemotherapy [3], orchiectomy + chemotherapy + RRRTM [4] and orchiectomy + radiotherapy [5]. An ANCOVA (for the two treatment categories and second cancer event) and a Scheffé test (for the five 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.

3. Results

3.1. 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; $t = 10.3$; $P < 0.0001$). The average education

level of the spouses was 3.9, which was significantly lower than that of the testicular cancer survivors (mean 4.2; $t = 2.7$; $P < 0.01$). 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 testicular cancer survivor since the completion of treatment. Spouses during testicular cancer were an average of 44.3 years of age (Standard deviation (SD)=11.6), while spouses after testicular cancer were an average of 36.7 years of age (SD=8.6). This difference in age was significant ($t = -3.9$, $P < 0.0001$). Mean duration of the relationship with a testicular cancer survivor was 20.9 years (SD=12.1) for the spouses during testicular cancer and 7.4 years (SD=5.5) for the spouses after testicular cancer. This difference was also significant ($t = -6.7$, $P < 0.0001$). 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 tes-

ticular cancer survivors of spouses after testicular cancer and spouses during testicular cancer. 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 of 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 ($P = 0.000$).

3.2. Differences in QoL between spouses and a reference group

QoL of the two spousal groups was compared with a reference group of women. An independent t test showed that spouses during testicular cancer had better physical functioning ($t = 4.3$, $P < 0.001$), fewer role limitations due to physical problems ($t = 3.6$, $P < 0.001$) and less pain ($t = 4.1$, $P < 0.001$) than a reference group of women. However, spouses during testicular cancer also reported poorer social functioning ($t = 2.1$, $P < 0.05$).

In common with spouses during testicular cancer, spouses after testicular cancer reported better physical functioning ($t = 3.6$, $P < 0.001$) than the reference group. However, in contrast with spouses during testicular cancer, spouses after testicular cancer reported

Table 1
Descriptives for the spouses and testicular cancer survivors

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

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

Table 2

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

| | Spouses during TC | | | Spouses after TC | | | Reference group | |
|--------------------------------------|-------------------|--------|--------|-------------------|--------|--------|-------------------------|--------|
| | Mean | (SD) | Range | Mean | (SD) | Range | Mean | (SD) |
| Physical functioning | 87.7 | (19.6) | 0–100 | 91.1 | (14.3) | 35–100 | 80.7 ^{ooo xxx} | (23.6) |
| Social functioning | 83.0 | (22.5) | 0–100 | 78.8 | (23.2) | 25–100 | 86.1 ^o | (20.9) |
| Role limitations – physical problem | 87.6 | (29.3) | 0–100 | 79.4 ⁺ | (35.3) | 0–100 | 78.3 ^{ooo} | (36.5) |
| Role limitations – emotional problem | 83.6 | (32.9) | 0–100 | 68.3 ⁺ | (42.7) | 0–100 | 82.5 ^x | (33.5) |
| Mental health | 76.1 | (15.2) | 20–100 | 68.7 ⁺ | (21.7) | 4–100 | 75.5 ^x | (18.9) |
| Vitality | 65.8 | (17.3) | 5–100 | 57.1 ⁺ | (22.3) | 10–100 | 66.3 ^x | (19.6) |
| Pain | 86.6 | (19.6) | 0–100 | 85.8 | (20.3) | 25–100 | 80.0 ^{ooo} | (25.4) |
| General health perception | 73.4 | (17.9) | 15–100 | 74.1 | (18.1) | 25–100 | 71.5 | (21.8) |
| Health change | 51.7 | (18.0) | 0–100 | 51.3 | (15.9) | 25–100 | 53.4 | (19.6) |

Comparison spouses during testicular cancer vs spouses after testicular cancer: ⁺ = $P < 0.05$ Comparison spouses during testicular cancer vs reference group: ^o = $P < 0.05$, ^{oo} = $P < 0.01$, ^{ooo} = $P < 0.001$ Comparison spouses after testicular cancer vs reference group: ^x = $P < 0.05$, ^{xx} = $P < 0.01$, ^{xxx} = $P < 0.001$.

QoL, quality of life; TC, testicular cancer.

more role limitations due to emotional problems ($t = -2.21$, $P < 0.05$), poorer mental health ($t = -2.0$, $P < 0.05$) and less vitality ($t = -2.6$, $P < 0.05$) than the reference group (Table 2).

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

3.3.1. QoL

An ANCOVA (with covariate age) showed that the spouses during testicular cancer had fewer role limitations due to physical problems ($F = 4.9$, $P < 0.05$), fewer role limitations due to emotional problems ($F = 4.7$, $P < 0.05$), better mental health ($F = 4.9$, $P < 0.05$) and more vitality ($F = 4.9$, $P < 0.05$) than the spouses after testicular cancer (Table 2).

3.3.2. Stress response

An ANCOVA (with covariate age) showed that spouses during testicular cancer reported more intrusion ($F = 4.2$, $P < 0.05$) and more avoidance ($F = 5.9$, $P < 0.05$) than spouses after testicular cancer and also reported more total stress response symptoms than spouses after testicular cancer ($F = 6.0$, $P < 0.05$) (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 with 0% in the spouses after testicular cancer.

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

3.4.1. 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 ($r = 0.22$, $P < 0.001$) and mental health ($r = 0.14$, $P < 0.05$) in spouses during testicular cancer were significantly correlated with those of the testicular cancer survivors. A paired t test showed one difference: spouses during testicular cancer reported better general health than the testicular cancer survivors ($t = -2.4$, $P < 0.05$).

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

3.4.2. 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

Table 3

Descriptives of the 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) | Range | Mean | (SD) | Range | Mean | (SD) | Range |
| Intrusion (possible range 0–35) | 5.3 | 6.5 | 0–28 | 3.3 ⁺ | 4.3 | 0–14 | 3.8 [*] | 5.3 | 0–30 |
| Avoidance (possible range 0–40) | 4.0 | 6.4 | 0–30 | 1.6 ⁺ | 2.6 | 0–10 | 3.5 | 5.8 | 0–35 |
| Total (possible range 0–75) | 10.9 | 14.0 | 0–61 | 5.6 ⁺ | 7.4 | 0–23 | 8.3 ^{**} | 10.9 | 0–58 |

Comparison spouses during testicular cancer vs spouses after testicular cancer: ⁺ = $P < 0.05$ Comparison spouses during testicular cancer vs testicular cancer survivors: ^{*} = $P < 0.05$, ^{**} = $P < 0.01$.

survivors on the two subscales intrusion ($r = 0.25$, $P < 0.000$) and avoidance ($r = 0.19$, $P < 0.01$), and regarding the total score ($r = 0.24$, $P < 0.001$).

A paired t test revealed that spouses during testicular cancer had significantly higher scores than testicular cancer survivors on the subscale intrusion ($t = -2.8$, $P < 0.01$) and the total score ($t = -2.3$, $P < 0.05$). 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 for the intrusion, avoidance and total stress response symptoms.

3.5. Treatment-related aspects and QoL and stress response of spouses

3.5.1. 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 or after testicular cancer.

3.5.2. Type of treatment

Spouses of men who underwent surgery alone were significantly younger than spouses of men who received combined treatments ($F = 4.6$, $P < 0.05$); no other sociodemographic differences in these groups were found. An ANCOVA (with covariate age) showed no effect of the extent of treatment on the QoL domains. This was found to be the case for both spousal groups. An ANCOVA (with covariate age) did show differences in the stress response symptoms. Spouses during testicular cancer of men who underwent surgery alone ($n = 74$) reported significantly fewer symptoms of intrusion ($F = 6.7$, $P < 0.01$) and less avoidance ($F = 5.1$, $P < 0.05$) 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 ($F = 8.1$, $P < 0.01$). In spouses after testicular cancer, no differences were found in the 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 five groups and analysed using a Scheffé test.

Table 4

Descriptives of stress response for different types of treatment

| | Surgical treatment (Orchiectomy \pm RPLND) | | | Combined treatment (Orchiectomy + RT or CT \pm RPLND) | | |
|---|---|--------|-------|--|--------|-------|
| | Mean | (SD) | Range | Mean | (SD) | Range |
| <i>Spouses during testicular cancer</i> | $N = 74$ | | | $N = 145$ | | |
| Intrusion | 3.7 | (5.7) | 0–22 | 6.1 ⁺⁺ | (6.8) | 0–28 |
| Avoidance | 2.7 | (4.8) | 0–21 | 4.7 ⁺ | (6.9) | 0–30 |
| Total | 7.2 | (11.3) | 0–49 | 12.7 ⁺⁺ | (14.9) | 0–61 |
| <i>Spouses after testicular cancer</i> | $N = 14$ | | | $N = 26$ | | |
| Intrusion | 4.2 | (4.9) | 0–14 | 2.9 | (3.9) | 0–13 |
| Avoidance | 1.8 | (2.5) | 0–8 | 1.6 | (2.8) | 0–10 |
| Total | 6.6 | (8.1) | 0–23 | 5.3 | (7.3) | 0–23 |

Comparison surgical treatment vs combined treatment:
+ = $P < 0.05$, ++ = $P < 0.01$.

RT, radiotherapy; CT, chemotherapy.

3.5.3. Second cancer event

Spouses during testicular cancer whose husband experienced a second cancer event were older ($t = -2.2$, $P < 0.01$) 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 men with a second cancer event was too small to analyse ($n = 4$).

4. Discussion

The aim of this study was to gain insight into the QoL 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 also had fewer emotional problems, better mental health and more vitality than spouses after testicular cancer.

In contrast, spouses during testicular cancer reported 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 difference 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 with those of 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 sometimes experienced 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 testicular cancer survivor. 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 previously studied 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, the 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 survivor might also affect our data. More extensive treatment might have more 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 treatments (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 testicular cancer survivor 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 a relationship after surviving cancer might provide more insight into these results.

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