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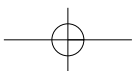
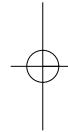
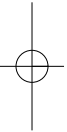
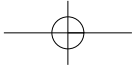
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**chapter 6 self esteem, social
support, and mental health in
survivors of testicular cancer:
A comparison based on
relationship status**

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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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