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Surviving testicular cancer

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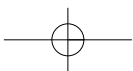
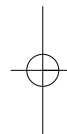
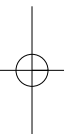
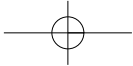
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chapter 4 **expression of negative emotions in testicular cancer survivors and their spouses**

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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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