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Surviving testicular cancer

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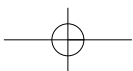
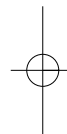
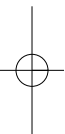
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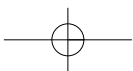
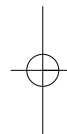
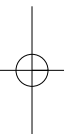
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chapter 8 **general discussion**





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

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

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

Overall conclusions

Functioning of spouses

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

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

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

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

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

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

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

Correspondence in functioning

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

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

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

Differences in functioning according to relationship status

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

Effect of medical, personal and social variables on functioning

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

Functioning of testicular cancer patients and survivors

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

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

Methodological considerations

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

Model of research and future research

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

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

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

Clinical implications

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

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

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

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

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

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

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