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Surviving testicular cancer

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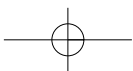
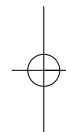
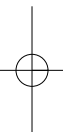
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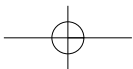
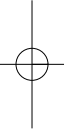
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chapter 1 **introduction**





Testicular cancer

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

Psycho-Oncology

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

Cancer and social relationships, especially with the spouse

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

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

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

Relationship status and functioning of cancer patients

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

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

Relevance for studying relationship aspects in testicular cancer patients and survivors

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

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

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

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

Research model

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

Outline

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

The general aims of the thesis are to study:

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

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

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

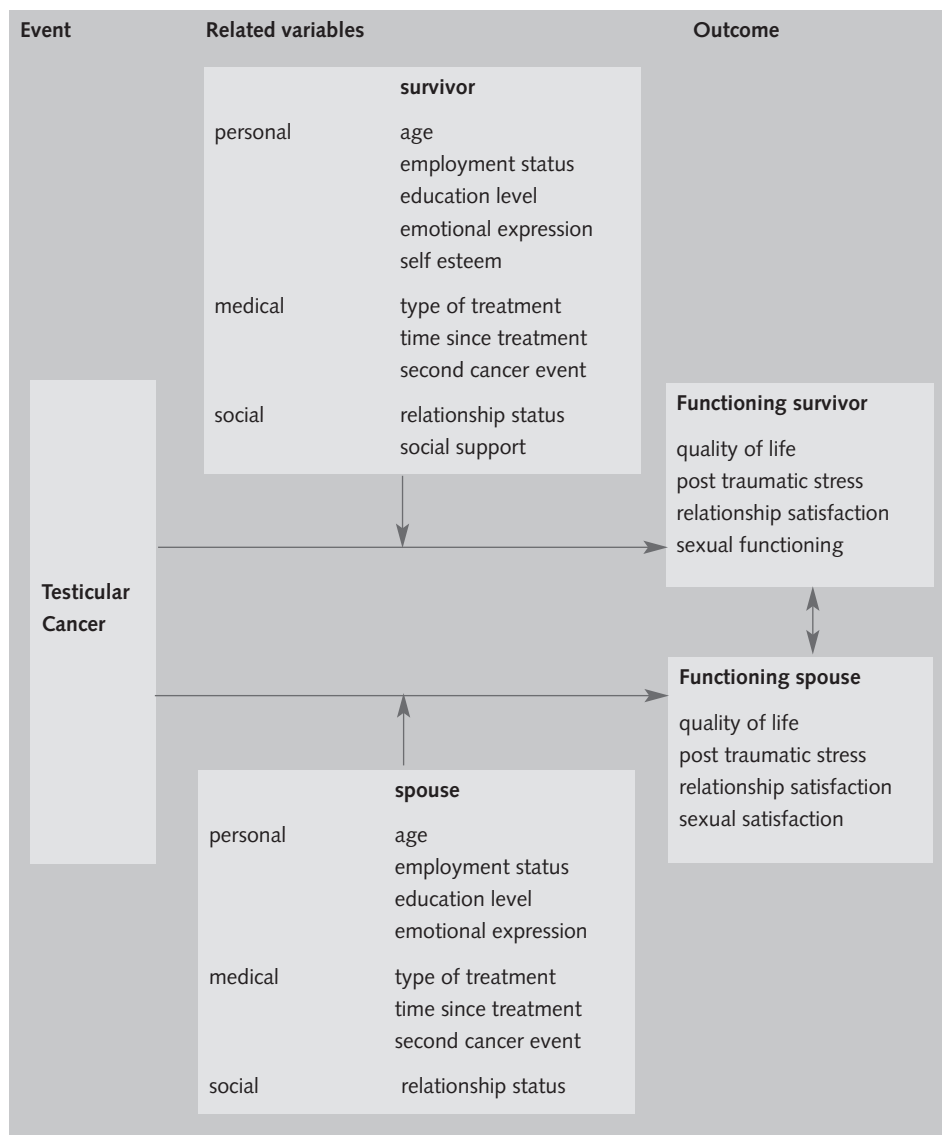


Figure 1 Schematic representation of the variables addressed in the thesis based on the model of research in psycho-oncology (Holland et al. 2002).

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