General discussion
General discussion

In the first part of this final chapter, some overall conclusions about the two primary research aims will be drawn. Then, some general methodological considerations of measurement approaches and recruitment strategies in quality of life studies of cancer survivors will be made. After that, the usefulness of the theoretical model that was used as a framework in this thesis will be discussed and suggestions will be made about directions for future research. The chapter will end with a discussion on the implications of the findings for clinical practice.

Overall conclusions

Quality of life of testicular cancer survivors

In the introduction of this thesis it was hypothesized that the specific combination of clinical features of testicular cancer may make a testicular cancer survivor vulnerable for an impaired quality of life. Our study results did not confirm this hypothesis. Findings of the present study indicate that, on the whole, testicular cancer survivors experience a good quality of life, which includes satisfaction with life, spiritual well-being (e.g., they consider their life as meaningful), and no lasting fatigue. In view of the finding that little or no effect of time since completion of treatment was found, one may conclude that this finding is valid for the short-, median-, as well as long-term survivors.

Does this mean that the cancer experience had no effect on the lives of the survivors at all, not even shortly after completion of treatment? The answer must be no. Firstly, these findings are based on answers to generic questionnaires. Such questionnaires often fail to show a reduction in the quality of life of people who have been diagnosed with a life-threatening or chronic disease, but this does not mean that the disease did not have an impact on a survivor’s life [1]. We also included disease-specific questions, which focused on the impact of the cancer experience on the current survivor’s life. The answers to these questions indicated that a small percentage did experience cancer-related distress (e.g., intrusive thoughts, nightmares) and did have a more negative outlook on life since testicular cancer (e.g., more anxiety and worries about the future, feeling more vulnerable and less in control). The majority reported, however, that their outlook on life had become more positive (e.g., more appreciation of life, reprioritizing what is important in life) and over half of the survivors stated that negative and positive effects of testicular cancer on their current life co-exist. These apparently opposing outcomes suggest that cancer may lead to distress as well as to positive personal growth. Yet, given the high overall valuation of quality of life, it does not seem that the reported distress interferes with everyday functioning in most of the testicular cancer survivors.

A second explanation offered for the finding that the testicular cancer survivors’ quality of life was comparable with that of people not confronted with cancer is that survivors may adjust by changing their internal standards, values and conceptualization of quality of life (i.e., response shift) [1], disengaging from some beliefs and goals and taking up others [2], or by finding positive benefit from the experience (i.e., meaning-making process) [3]. However, the design and methodology of our study did not allow us to capture such processes possibly used by survivors to adapt to their changed life situation.
Predictors of quality of life of testicular cancer survivors

Although most of the testicular cancer survivors appear to function well, a minority did report lower levels of quality of life and clinically elevated levels of cancer-related stress symptoms. This minority might benefit from psychosocial help. To detect these individuals we investigated if characteristics of the disease and treatment, personal variables, and life stresses were risk factors for an impaired quality of life or cancer-related distress.

The relationship of objective disease- and treatment-related characteristics (i.e., time since completion of treatment, type of treatment, second cancer event, and hemoglobin-, and testosterone levels) with the outcome variables was weak to negligible. This finding contradicts with clinical intuition. For instance, one would suppose that a testicular cancer survivor treated with surgery and chemotherapy would experience more physical and psychosocial late-effects then a patient treated with surgery only. Nevertheless, this study was not the only one to show a lack of effect on quality of life of objective characteristics of disease and treatment. Our findings are in line with what is often reported in the literature: objective disease- and treatment-related characteristics are weak predictors of well-being. Findings of this study, as well as of many earlier studies (e.g., [4-7]), suggest that subjective perceptions may be more important determinants of functioning. We found, for example, that testicular cancer survivors who still perceive a negative impact of testicular cancer on their current lives (e.g., intrusive memories and changes in daily life as a result of late effects of treatment for testicular cancer) and those who report more anxiety about the future (e.g., fear for recurrence or medical problems) show more distress.

The personal variables and life stresses that related to an impaired well-being in testicular cancer survivors were: unemployment, not doing what feels meaningful, an anxious disposition, concurrent chronic disease, and the experience of a cumulative number of negative life events. Associations between these variables and (aspects of) quality of life have also been found in the general population, indicating that the testicular cancer survivors do not deviate from the normal population in risk pattern. Still, knowledge of these risk variables is relevant, because it may assist clinicians in their attempt to identify individuals who will have difficulty adjusting.

In sum, this thesis provides more insight into factors that affect quality of life of testicular cancer survivors. However, based on this attained knowledge it will still be difficult for health care providers to identify survivors at risk for continuing cancer-related distress. Therefore, more research is needed to identify further factors that relate to their quality of life. The predictor variables under investigation were derived from the research model of Holland and colleagues [8]. In the paragraph “Theoretical reflections and future research” we will discuss whether this model provides a useful framework for future research and suggestions will be made about directions for research. First, however, some methodological considerations will be discussed.

Methodological considerations

The studies described in this thesis all include a section in which the strengths and weaknesses of the used designs and methods (e.g., response rate, range in time since treatment) are discussed, and thus, these reflections will not be repeated here. However, there are two additional
methodological issues that we want to discuss comprehensively here. This section will focus on measurement approaches and recruitment strategies.

The design and methodology of our study did not provide the opportunity to capture the cognitive processes that cancer survivors use to come to a judgment of their quality of life. We used traditional questionnaires, in which the weighting of the domains (e.g., physical functioning, social functioning, mental health) was fixed. However, these domains may not have the same relevance or importance for all individuals. Furthermore, the relevance or importance of a particular domain does not necessarily remain static with the passage of time or after major life events, such as cancer [9]. For instance, a cancer survivor can experience objective physical limitations and problems as a result of chemotherapy, but still evaluate his quality of life as satisfactory because the experience with cancer has made him realize that it is far more important to spend quality time with his family than to feel physically fit. Individualized measures of quality of life (e.g., SEIQoL) do allow respondents to indicate which areas of life are most important, rate their level of functioning or satisfaction with each, and indicate the relative importance of each to their overall quality of life [10]. A multi-method approach (i.e., both quantitative and qualitative measurement instruments) may be informative as well, as much is yet to learn about the cognitive processes cancer survivors use to come to a judgment of their quality of life and how the cancer experience has influenced the value that survivors attribute to the different domains of quality of life [11]. Since quality of life assessment is increasingly used as a major outcome parameter in health care, both for clinical decisions and policy making, it is vital that the measurement of quality of life accurately reflects how patients arrive at their appraisal and how it should be interpreted.

Another impediment of traditional measurement approaches is that they are mostly focused on limitations and problems, without considering positive elements that contribute to quality of life. Linking-up with many other studies (e.g., [12;13]), this study shows that cancer can have a positive as well as a negative impact on quality of life. Measurement of quality of life should therefore include the possibility that it can be evaluated both in positive and negative terms. Recruitment is the second methodological consideration of concern for both researchers and health care providers of cancer patients and survivors. We found that recruitment through different sources identifies populations with different characteristics and that this has an impact on quality of life outcomes. This finding stresses the importance of presenting information about recruitment strategies in articles, because that gives the reader the opportunity to value a study at its worth [14]. If results are not generalizable to the population of patients under study, it is not possible for the oncologist to give solid advice to patients on relevant issues.

Usefulness of theoretical model and future research

The model used as a framework for this thesis (see Figure 1) was derived from the research model developed by Holland and colleagues [8]. This research model proved useful for the identification of factors possibly related to outcomes (e.g., quality of life, distress). Therefore, the model can be used to identify further possible predictors (e.g., personality variables and coping styles, illness-related behaviors, doctor-patient communication). However, despite the usefulness of this research model for the categorization of possible risk variables, it may be less useful as a framework for guiding research whose goal is to capture the adaptation process. Other frameworks, such as stress-coping theory (e.g., [15]), response shift theory [1] or the
theory on self-regulation [2] may provide better guidance in understanding the process of adapting to changes in life situations.

Based on the findings in this thesis, there are some more suggestions for future research. First, the conclusion that the most distressed survivors are those who still experience a threat from their cancer experience on their lives needs further validation, because it was based on the answers of only 30 testicular cancer survivors. We believe that this is a relevant topic to study in this patient population, because a recently published, qualitatively strong study found that a very high proportion of testicular cancer survivors (31%) reports fear for a recurrence at a mean of eleven years after treatment completion [16]. Results from research in other types of cancer also indicate that the degree of anxiety, or worry, may be an important component of overall adjustment (e.g., [17;18]). Moreover, the preoccupation with current threat of the disease has been incorporated into the DSM-IV [19] and the theoretical model of Ehlers and Clark’s [20] cognitive model of persistent posttraumatic stress disorder. This model of Ehlers and Clark may prove a useful theoretical framework for research into cancer-related distress.

Second, our finding that having an additional chronic disease related to an impaired well-being needs additional investigation, especially because a recent study also found that self-reported side-effects of treatment are strongly associated with reductions in quality of life in testicular cancer survivors [21]. It might be that self-perceived physical impairments, whether they are induced by the treatment for testicular cancer or not, may make testicular cancer survivors more vulnerable. There is one model that specifically focuses on the underlying relationships between self-reported physical impairments and the experience of an impaired well-being and, thus, may be more effective in unraveling the mechanisms in testicular cancer survivors than the stress-coping paradigm: the illness-intrusiveness theoretical framework of Devins et al. [22;23]. This theory maintains that illness- and treatment-related disruptions may interfere with continued involvements in valued activities and interests and plans for the future, which may lead to lower levels of overall quality of life. Testicular cancer patients are diagnosed in the prime of their life, when career, interpersonal relationships and starting a family are major issues. With the use of this theoretical framework, future research may elicit if the after-effects of illness does indeed intrude on the planned life trajectories of these men and represents an underlying stressor that contributes to distress in testicular cancer survivors.

Third, researchers might want to investigate the relationship between meaning and cancer-related distress. We found that having a sense of meaning was related more strongly to quality of life than to cancer-related distress. This suggests that having a sense of meaning is more important to the experience of positive quality of life than to coping with cancer-related post traumatic stress symptoms. Yet, it has also been argued that having a sense of meaning provides a resource that facilitates successful coping with severe life stressors [3;24-26]. Therefore, more research is needed to investigate the underlying mechanisms between meaning and cancer-related distress. Both the revised model of stress and coping [15] and the model of global and situational meaning [3] may serve as a frame for this research.
Clinical implications

Most testicular cancer survivors experience a good quality of life and are not in need of a psychosocial intervention, but a minority does experience cancer-related distress and might benefit from such an intervention. Yet, how can clinicians detect these distressed individuals? They cannot base their judgment on the disease- and treatment-related characteristics of the survivor, because the impact of these factors on quality of life and cancer-related distress appeared to be minimal. In this thesis we suggested a way to identify distressed testicular cancer survivors, and we found that those who still experience a threat from their cancer experienced the highest level of distress. Therefore, it might be useful to ask testicular cancer survivors during their check-ups about their thoughts concerning the threat of testicular cancer for their current and future lives, as these perceptions do not necessarily coincide with actual state of health [4]. Testicular cancer survivors who feel that their life is still threatened by cancer may benefit from a discussion with their physician about the possible late effects of testicular cancer. Additional cognitive-behavioral therapy, which tends to focus on replacing unrealistic beliefs with realistic beliefs and teaches individuals how to cope with difficult situations, may help them to accept the uncontrollable aspects of their life situations (e.g., chance of recurrence and possible late effects). Furthermore, it may help to redirect their energy to the controllable aspects of their lives (e.g., diet, smoking cessation, exercise), help them to reframe the experience in a positive light (i.e., meaning-making process), and if necessary, guide them in generating new, valued and realistic goals.

---

**Figure 1. Schematic representation of the research model in psycho-oncology of Holland and colleagues [8]**

<table>
<thead>
<tr>
<th>Testicular cancer</th>
<th>Related variables</th>
<th>Outcome variables</th>
</tr>
</thead>
</table>
| Personal variables | - sociodemographic characteristics  
- meaning  
- trait anxiety | Quality of life (multidimensional)  
Cancer-related stress symptoms  
Meaning  
Satisfaction with life  
Fatigue (multidimensional) |
| Life stresses | - concurrent chronic disease  
- recently experienced life events | |
| Disease and treatment variables | - time since treatment  
- type of treatment  
- second cancer event  
- hemoglobin level  
- testosterone level | |


