

# TOWARDS A RETAINED HEALTH IN TESTICULAR-CANCER PATIENTS – LONG-TERM COGNITIVE FUNCTION, MISSING A TESTICLE AND PSYCHOLOGICAL NEEDS

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Sahlgrenska Akademin vid Göteborgs Universitet offentligen försvaras i Hjärtats aula, Sahlgrenska Universitetssjukhuset, Vita stråket 12

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av

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## Avhandlingen baseras på följande delarbeten:

- I. Skoogh J, Steineck G, Stierner U, Cavallin-Ståhl E, Wilderäng U, Wallin A, Gatz M, Johansson B on behalf of SWENOTECA. Testicular-Cancer Survivors Experience Compromised Language following Chemotherapy: Findings in a Swedish Population-based Study 3 - 26 years after Treatment. *Acta Oncol.* 2012 Feb; 51(2):185-197.
- II. Skoogh J, Steineck G, Johansson B, Wilderäng U, Stierner U on behalf of SWENOTECA. Psychological crises among testicular-cancer survivors – results from a population-based long-term follow-up. Submitted Manuscript
- III. Skoogh J, Steineck G, Cavallin-Ståhl E, Wilderäng U, Håkansson U, Johansson B, Stierner U on behalf of SWENOTECA. Feelings of loss and uneasiness or shame after removal of a testicle by orchiectomy: a populationbased long-term follow-up of testicular cancer survivors. *Int J Androl.* 2011 Apr; 34(2):183-92.
- IV. Skoogh J, Ylitalo N, Larsson-Omérov P, Hauksdottir A, Nyberg U, Wilderäng U, Johansson B, Gatz M, Steineck G on behalf of the Swedish-Norwegian Testicular Cancer Group. "A no means no"-measuring depression using a single-item question versus Hospital Anxiety and Depression Scale (HADS-D). Ann Oncol. 2010 Sep; 21(9):1905-9.

# ABSTRACT

**Background:** Many breast-cancer survivors experience chemotherapy-induced cognitive decline. Our knowledge about potential cognitive side-effects among testicular-cancer survivors is, however, sparse. We also lack information concerning these men's psychological health and needs, at diagnosis as well as over time.

#### Aim:

The main aim of this thesis was to investigate whether chemotherapy leads to long-term decreased selfreported cognitive function among testicular-cancer patients or not. We also wanted to get a deeper understanding of the psychological needs in this population.

#### Methods:

We identified 1173 eligible men diagnosed with non-seminomatous testicular cancer treated according to the bi-national cancer-care programs SWENOTECA I-IV between 1981 and 2004. During an 18-month qualitative phase we constructed a study-specific questionnaire built on information gained from interviews with cancer survivors. In these interviews, problems emerged concerning the survivors' cognitive function, their feelings of loss concerning the testicle or testicles that had been removed, and also the men's statements that they would have appreciated more psychological care during both diagnosis and treatment. Following these interviews, we continued by making a quantitative study where all these issues were taken up, however, with a focus on cognitive function.

### **Results:**

In 2007 we obtained information from 960 of 1173 (82%) testicular-cancer survivors diagnosed on average 11 years previously. We found that a higher percentage of the survivors who received five or more cycles of chemotherapy, compared with those who received no chemotherapy, reported language difficulties in five of the seven language questions included in the questionnaire, with p-values ranging from 0.0002 to 0.0266. Two thirds of Swedish testicular-cancer survivors report they experienced a crisis due to their diagnosis. A similar percentage of the men report that they wish they had received information about common stress and crisis reactions and had been offered counseling. Furthermore, we found that 26 percent have or previously had feelings of uneasiness or shame about their body because of the removed testicle(s). Among the 794 men who answered "No" to the single-item question "Are you depressed?", 790 (99.5%) were not considered as depressed according to HADS-D 11+.

#### **Conclusions:**

We found that Swedish testicular-cancer survivors who received five or more cycles of cisplatin-based chemotherapy experience an increased incidence of compromised language. Furthermore we found that some men miss their testicle or testicles and that many testicular-cancer patients have psychological needs that are not satisfactorily met by the health-care professionals.

#### **Implications:**

We believe all testicular-cancer patients should receive information about possible cognitive sideeffects after treatment with chemotherapy as well as common psychological reactions when being diagnosed with cancer. By increasing preparedness and normalizing symptoms and reactions we might decrease long-term morbidity in this group of men.

**Keywords:** testicular-cancer patients, testicular-cancer survivors, chemotherapy, cognitive function, compromised language, single-item question, depression, feelings of loss, feelings of shame, psychological needs, crises.

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