



# Karolinska Institutet

**Institutionen för Neurobiologi, Vårdvetenskap och Samhälle**

## **Influence of childhood cancer on adult life**

**Quality of life, health status, sexual function and  
sense of coherence**

**AKADEMISK AVHANDLING**

som för avläggande av medicine doktorsexamen vid Karolinska  
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## ABSTRACT

Treatment related health problems are widely acknowledged in the growing population of long-term survivors of childhood cancer. The overall aim was to investigate the influence of childhood cancer on quality of life and health in long-term survivors to increase the understanding for their needs for support in adulthood. The four studies used a cross-sectional design and were based on interview data and self-completed questionnaires. The survivor sample consisted of 246  $\geq 18$  years old long-term survivors ( $>5$  years beyond diagnosis), diagnosed at ages 0-18 during the period 1985-1999 in the greater Stockholm area. In Study I, consequences due to the cancer experience were investigated through telephone interviews based on the Swedish version of the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting. In Study II-IV, a comparison group consisting of 296 persons randomly selected from the general population was included. Two standardized instruments were used assessing health status (Short Form Health Survey, SF-36), and coping capacity (Sense of Coherence, SOC), as well as a questionnaire evaluating sexual function and experience.

The survivors described and rated quality of life and health status similar to the comparison group. Nearly one third of the survivors reported no negative impact on life due to the cancer experience, and half of the survivors described a positive view of life and self. The most frequently reported negative consequences include a variety of physical impairments and activity limitations. The survivors differed from the comparison group on one of eight health scales reflecting problems with daily activities owing to physical health. Male survivors reported sexual dysfunctions more often than men in the comparison group did. The sexual dysfunctions were associated with being single and diagnosed with central nervous system tumour. There were differences regarding sexual experience but not regarding sexual function among the women. There was no significant difference in the mean SOC score between the survivors and the comparison group. The 20% of the survivors who reported a current need for support also reported a significantly lower mean SOC score. A low SOC score and having received combined cancer treatment were strong predictors of having a need for support.

The results reveal both positive and negative aspects of the disease and treatment. At the group level, the survivors reported few health problems and overall good quality of life. Sexual difficulties were not frequently reported by the survivors. The results indicate however, that childhood cancer had some impact on self-reported sexual function among men and in sexual experience among women. Overall, the survivors appear to have the resources needed to cope with stressful situations in life to the same degree as people in general. However, a lower SOC was associated with having a need for support. Furthermore, the findings show that the influence of childhood cancer varies between different subgroups of survivors, why it is important to identify problems and needs for each individual. Understanding how long-term survivors of childhood cancer perceive adult life is important to the practice of nursing because it will offer the possibility to provide guidance and support for patients and their families during and after treatment.

*Keywords:* Childhood cancer, long-term survivors, young adult, quality of life, health status, sexual function, sense of coherence